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**“I understand that I am me, but that I am also we”:
The Contemporary Literary & Cultural
Construction of Conjoined Twins**

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Introduction

On September 30, 2003, the New York Times published an article by Denise Grady about conjoined twins, Carl and Clarence Aguirre, titled “Two Boys, Joined Skulls, One Goal: Two Lives”. The titular word play with singularity and plurality illuminates one of the primary concerns that conjoined twins call into question: what it means to be a self, bounded by a single body, independent of others. The idea of an autonomous, singular subject is a construct that is tested by the body of conjoined twins—a body that seems to dissolve the fixed borders of the self and opens up to negotiation the relation between self and other. Embedded in this argument is a secondary concern with the ways that different discourses and sites of representation either discipline non-normative bodies in an attempt to preserve an ordered, normative form of the so-called natural or ideal body or open these naturalized notions to alternative possibilities. As the newspaper article’s title indicates, separated conjoined twins are a reason to celebrate; they are “media miracles”¹ as well as medical miracles. At the same time, however, the resistant bodies of conjoined twins challenge prevailing notions of subjectivity, ‘normalcy’, and physical difference. These challenges lie at the heart of this thesis and are reflected in its title—“I understand that I am me, but that I am also we”—taken from the novel *The Girls* (2007).

Conjoined twins are a prime, but as yet undertheorized example of bodily difference. Their figuration has served historically as the canvas upon which society has projected its anxieties, most noticeably in the context of the nineteenth-century freak show, and they have emerged once again, at the turn of the twenty-first century, in a similar role. Despite the fact that conjoined twins are rare, accounting for approximately one in 200,000 live births,² they have attracted tremendous attention of late. In keeping with Rosemarie Garland-Thomson’s observation that extraordinary bodies “function as magnets to which culture secures its anxieties, questions, and needs at any given moment”, the renewed

¹ The term ‘media miracles’ is used by Michelle Imison and Simon Chapman in their unpublished conference paper, “Media Miracles: The Separation of Conjoined Twins, and Reflections on Minimal Television News Coverage of Health from Low- and Middle-Income Countries” (2006).

² This number varies significantly between sources. J. David Smith claims that the incidence is “somewhere between once in every 50,000 to 80,000 births” (1988: 4). Alice Dreger claims that they “account for perhaps as few as one in 200,000 births and no more than one in 50,000” (2004: 6).

interest in the figure of conjoined twins raises the question of what cultural demand their representations satisfy and what ideologies their shared body expose and subvert (1996: 2).

Representation and Conjoined Twins

In his lecture, “Representation and the Media” (2005), Stuart Hall outlines two meanings of representation that inform this thesis: “to offer a depiction of something else” and “that which stands in for something else” (6). The former involves *re*-presentation, a process that this thesis—as an examination of documentary film, television, and fiction—addresses extensively. The latter, however, is equally important in that representations of any non-normative body can either reinforce or subvert ideologies of ‘normalcy’.

Conjoined twins come to represent or stand in for something or someone else in at least three different ways. First, the conjoined twins that are depicted in various texts stand in for other conjoined twins—a very small group of people who are physically joined in myriad ways and who therefore experience their conjoinment much differently from other sets of conjoined twins and perhaps even the twins to whom they are joined. Second, they have the potential to stand in for other non-normative bodies in general. The inherent danger of this representation is conflating the individual with the collective. While it may be politically advantageous for marginalized groups to come together—to stand against discrimination, for example—when ‘one’ stands in for all, the significance of individual experience is drastically diminished or obliterated. While conjoined twins may not consider themselves disabled (a possibility that I discuss later), their non-normative bodies may ultimately be seen as constituting a disability, and this may result in them becoming representative of other disabled people. Any representation of disability runs the risk of being reductive because the experience of ‘one’ individual with a specific disability does not necessarily mirror the experience of another with the same impairment or disability³. Further, that

³ Throughout this thesis, I maintain a distinction between ‘impairment’ and ‘disability’. ‘Impairment’ refers to a condition that most likely causes a loss or change in function. It relates to the function of a part of the body. ‘Disability’, on the other hand, is the oppression that someone

same representation runs the risk of standing in for people with various impairments. Third, the figure of conjoined twins represents a variety of twenty-first-century cultural anxieties about subjectivity, physical difference and 'normalcy', and the understanding of the body as socially and/or biologically constructed, all of which overlap extensively, as this thesis will demonstrate.

The anxieties conjoined twins come to represent can be explored further by drawing on Irving Goffman's use of the term 'stigma'. For Goffman, stigma is the evidence of difference that makes someone appear less than desirable or weak; broadly defined, it is "an undesired differentness" (1986: 5). One of Goffman's categories of stigma, "abominations of the body" (ibid: 4) or physical deformities, is particularly relevant to my argument because it is this material difference that causes us to reduce the stranger before us "from a whole and usual person to a tainted, discounted one" (ibid: 3).

One of the key questions that arises and that is dealt with through representations of conjoined twins is whether this physical difference is naturally or culturally constituted. In her essay, "Stigma: An Enigma Demystified" (1997), Lerita Coleman posits stigma as a response to the physical or material mark that Goffman describes. Coleman problematizes the emphasis on physical difference, but does not dismiss its power entirely. She maintains that physical abnormalities "may be the most severely stigmatized differences because they are physically salient, represent some deficiency or distortion in the bodily form, and in most cases are unalterable" (217-18). Stigma, in her estimation, has evolved from a physical marking into a social tool, acting as a "way to maintain order in a potentially chaotic world of social stimuli" (221). Coleman maintains that "[s]tigma represents a view of life; a set of personal and social constructs; a set of social relations and social relationships; a form of social reality" (216). For her, stigma begins with a mark of physical difference, such as those mentioned by Goffman, but this difference derives meaning through interpretation and thereby becomes a social construction.

Similar questions have been raised in the context of recent debates regarding the relation between the sexed body and social inscription. Focusing on

with an impairment faces. It involves the interaction between a person with an impairment and his/her environment.

discourse as the means through which identities and bodies are constructed and re-constructed, Judith Butler postulates, in her theory of performativity, a subject that is constantly becoming and evolving through the repeated acts that it performs:

Performativity cannot be understood outside of a process of iterability, a regularized and constrained repetition of norms. And this repetition is not performed *by* a subject; this repetition is what enables a subject and constitutes the temporal condition for the subject. (1993: 95; her emphasis)

Again, even this act of construction begins with a physical mark of difference. In *Bodies that Matter* (1993), Butler states "that there are, minimally, sexually-differentiated parts, activities, capacities, hormonal and chromosomal differences that can be conceded without reference to 'construction'" (10), but she is careful to qualify her position by pointing to the inherent problem of assuming "a pure body which is not at the same time a further formation of that body" (ibid). Butler recognizes the "inevitable practice of signification, of demarcating that to which we then 'refer'" (ibid).

The sexed body can be compared to the physically different or anomalous body. While there may exist a material base, it is always further substantiated through discourse. To describe material reality *per se* is problematic because

any act of description [...] marks a boundary that includes and excludes, that decides, as it were, what will and will not be the stuff of the object to which we then refer. This marking off will have some normative force and, indeed, some violence, for it can construct only through erasing; it can bound a thing only through enforcing a certain criterion, a principle of selectivity. (ibid: 11)

The dynamics of inclusion and exclusion are explored in chapter one in my analysis of the freak show. The physically different subjects of the freak show are excluded from the realm of 'normalcy' not by their mark of difference alone, but by the repeated acts that they perform and are made to perform as anomalous bodies, as 'freaks'.

Feminist philosopher Elizabeth Grosz also points to the tension between the raw material of the body and processes of social inscription. In contrast to Butler and Coleman, however, Grosz argues more strongly in favor of corporeality. She writes of human bodies in general that "[p]art of their own 'nature' is an

organic or ontological 'incompleteness' or lack of finality, an amenability to social completion, social ordering and organization" (1994: xi). In other words, the raw material of the body is the open end to which culture seeks to assign meaning. For Grosz, the material body does not dissolve in the process of social construction and should always be thought of as both—"a thing and a non-thing, an object, but an object which somehow contains or coexists with an interiority, an object able to take itself and others as subjects, a unique kind of object not reducible to other objects" (ibid). While Grosz makes this statement about all bodies, it seems especially applicable to physically different bodies, which are socially constructed but also unsettle and influence discursive classifications in their material difference. Rosi Braidotti, who, like Grosz, is invested in models of corporeality that point to the limitations of social constructionism, has explored this dynamic with regard to the anomalous or monstrous body. She reminds us: "Monsters are not just one object of scientific inquiry. [...] If they can be called an object at all, they are one which is the effect of, while being also constitutive of, certain discursive practices" (1999: 299-300).

The difficulty is finding a balance between the cultural and the natural, and resisting what Grosz calls an "oversimplification" of either: "[T]he hole in nature that allows cultural seepage or production must provide something like a natural condition for cultural production; but in turn the cultural too must be seen in its limitations, as a kind of insufficiency that requires natural supplementation" (1994: 21). Terry Eagleton, writing about the limitations of critical theory, also reminds us that

this resolute anti-dualism, though salutary enough in its way, is untrue to a lot of our intuitions about the lump of flesh we lug around [and] the fact remains that the human body is indeed a material object, and this is an essential component of anything more we get up to [...]. It is not quite true that I have a body, and not quite true that I am one either. (1993: 7-8)

The challenge in grasping the body is to think of it as both an ontological reality, as well as an object that can be possessed or known, an epistemological construct. Grosz, like Eagleton, problematizes a naïve understanding of the material body, but also challenges the idea that the body is entirely imprinted by culture and history. Rather, she seeks a fuller awareness that combines both approaches and promises a more nuanced understanding of embodied subjectivity, recognizing

the body as a biological and psychical entity positioned in, but also exerting influence on, a changeable cultural context.

The complex understanding of the body that Grosz and others advocate mirrors the current drive in disability studies to see disability as more than “a representation, a cultural interpretation of physical transformation or configuration” (Garland-Thomson 1997: 6). This interest in the relation between the physical and the cultural and related questions of ‘normalcy’ and subjectivity are represented by the figure of conjoined twins in the twenty-first century. As reflective, quite literally, of the blurring of boundaries, representations of conjoined twins are used to engage more critically with ideologies of, for example, disability and sexuality that naturalize difference.

Representation & Power

In addition to the meanings of representation mentioned above—as standing in for and portraying something—Stuart Hall addresses another component of representation that is particularly relevant to my analysis of the figure of conjoined twins:

Now, we’re talking about representation, not as an after-the-event activity; it means something and then the presentation might change or distort the meaning. We’re talking about the fact that it has no fixed meaning, no real meaning in the obvious sense, *until* it has been represented. [...]

Now what this means is in fact the process of representation has entered *into* the event itself. [...] [R]epresentation doesn’t occur *after* the event; representation is *constitutive* of the event. It enters into the constitution of the object that we are talking about. [...] It is one of the conditions of existence [...] (1997: 7-8; his emphasis).

The notion that something lacks a meaningful existence until it is represented is reminiscent of debates surrounding the body discussed above. Hall calls into question whether an object/event has its own inherent meaning or lacks a meaningful existence until it is constructed through representation. He does not refute pre-representational existence, but questions the idea that ‘something’ can have a *true* meaning before it has been represented. He claims “the true meaning of it will depend on what meaning people make of it; and the meanings they make of it depends on how it is represented” (ibid: 7). Like Grosz and Braidotti, as well

as Butler, Hall does not deny the ‘it’. In fact, he says, “The statement, ‘Nothing exists outside of discourse,’ is a sort of claim that, as it were, there is no material existence, no material world form, no objects out there, and that is patently not the case” (ibid: 12). As Hall articulates, “[l]anguage *externalizes*—it makes available and accessible as a social fact, a social process—the meanings that we are making of the world and of events” (ibid: 11; his emphasis). Thus the object requires discourse to make sense: “[...] without language, no representation; without language, no meaning” (ibid: 13).

Because of this process of representation, one must also question the circulation of meaning, which “almost immediately involves the question of power. *Who* has the power, in *what* channels, to circulate *which* meanings to *whom*? Which is why the issue of power can never be bracketed out from the question of representation” (ibid: 14; his emphasis). Hall discusses ideology as the result of power inserting itself into representation in order to secure to the ‘it’ “[...] one true meaning [...]” (ibid: 19) so that “a relationship between the image and a powerful definition of it [...] becomes[s] naturalized so that *that* is the only meaning it can possibly carry (ibid; his emphasis). Stereotyping, according to Hall, is one example of an attempt to fix meaning, and the solution, he says, is not to “*reverse*” (ibid: 20; my emphasis) but to “open up stereotypes” (ibid) to alternative, diverse possibilities.

This strategy of opening up stereotypes is significant to my analysis of conjoined twins on several levels. Returning once again to the three groups that conjoined twins may stand in for (other conjoined twins, other disabled people, and a variety of twenty-first-century anxieties) and the ways in which they are represented through a variety of media, it is important to examine the upsurge in the representation of conjoined twins and attempt to explain how and to what extent their representation functions in regulatory or subversive ways. It is not, as Hall makes clear, as simple as balancing positive and negative images, but rather a process by which stereotypes and ideologies are turned “against themselves; to open, in other words, the very practice of representation itself—as a practice—because what closure in representation does most of all is it naturalizes the representation to the point where you cannot see that anybody ever produced it” (ibid: 21). The critical study of representation, on the other hand, can “*change* the

relationship of the viewer to the image” and open up a space of critique (ibid: 21; his emphasis). My thesis deals with the double-meaning of representation as a form of ‘standing in’ as well as *representation*; it also engages with the process of representation as constitutive of stereotypes, ideologies and other social and cultural norms. Overall, my thesis raises the question of how the figure of conjoined twins is used in documentary, television, and fiction to reinforce, but also challenge such norms and ideals.

Conjoined Twins in Contemporary Fiction and Culture

The cultural interest in conjoined twins is apparent in the recent increase of representations of conjoinment. In addition to the four novels that I discuss in chapters four and five, several other fictional and semi-fictional texts have been written since 2000⁴. Recent works about Chang and Eng Bunker include *Chang and Eng* (2000), a fictional retelling from the perspective of Eng, by Darin Strauss. It begins when the twins are children and follows them through various personal journeys—as international circus acts, as brothers, husbands and fathers, and as ordinary men confronting issues of identity formation. Strauss emphasizes the differences in their personalities as well as the differences in the ways they view their conjoinment. For example, Eng describes the first time he and Chang saw other children. At just eight years old, he recalls

[h]ow odd these separated youngsters were, and how lovely? I had assumed disconnection was for adults only. And now, hanging from the fishing lines, Chang and I looked upon these creatures the way seafarers would their first mermaid.

“They are half formed!” Chang whispered. To me they seemed liberated. This world, I understood then, had been created without thought of me. (23).

God’s Fool (2002), by Mark Slouka, is told primarily from Chang’s perspective, and like Strauss’ retelling, offers an examination of the brothers’ lives as travelling sideshow performers and as residents of the American South prior to the Civil

⁴ Conjoined twins have appeared in fiction before 2000 as well. In 1894, for instance, Mark Twain included “Those Extraordinary Twins” in the appendix of the novel *Pudd’nhead Wilson*. “Scenes from the Life of a Double Monster” was written in 1950 by Vladimir Nabokov, followed by John Barth’s short story, “Petition”, in 1968 and Judith Rossner’s novel, *Attachments*, in 1977. In addition to the recent novels I discuss above that feature Chang and Eng Bunker, Amy and Irving Wallace wrote *The Two: The Story of the Original Siamese Twins* in 1978.

War. This narrative account of their lives often pits Chang and Eng against each other and draws parallels between their deteriorating relationship and the struggles between the American North and South. In addition, it connects their bodily conjoinment, the fact that they are 'chained' to one another, to issues of slavery that divided the country. While *Chang and Eng* placed greater emphasis on Eng's individual experience of his conjoinment, Slouka's novel emphasizes the twins' adventures as seen through Chang's eyes.

The Boys from Siam (2008), by Irish author John Connolly, is a play about Pigg and Pegg based loosely on the lives of the Bunkers. Winner of the Yale Drama Series, the play dramatizes the twins' struggle to be seen as 'normal' despite their extraordinary bodily difference. When Pigg discovers one morning that Pegg is dying, they reminisce about their past before Pigg realizes that his only means of survival is using a razor to separate him from his dying brother. Like the two novels, Connolly's play reflects upon subjectivity, but its use of dual voices adds another dimension, pointing to the open-ended relation between mind/body and self/other.

The various interpretations of the lives of the iconic twin brothers point to a current fascination with the 'original' Siamese twins⁵. While these texts are dedicated to telling the stories of their lives exclusively, other novels (including those that I discuss later) often mention the twins as a means of evoking a history of conjoined twins that is shared even hundreds of years later. This desire to understand and be connected to a collective past is also apparent in fiction that uses the freak show as a setting. These novels include *Cabinet of Wonders* (2006) by Renee Dodd, which describes the lives of several acts in the 1927 Starlight Carnival Royale, a travelling freak show. Molly and Faye, one of the show's most popular and lucrative acts, are conjoined teenagers, who face the typical trials of adolescence, such as rebellion and sexual awakening, on the road. Dodd reverts the stereotypical view of 'carnies as outsiders' by positioning the performers as a rather ordinary family that faces the same problems as any other. The people who come to see them, on the other hand, are presented as outsiders. *Cirkus* (2007), by Patti Frazze, is set in 1900 in the Midwest of the United States. Conjoined twins

⁵ See the forthcoming book by Cynthia Wu: *Chang and Eng Reconnected: The Original Siamese Twins in American Culture*. Philadelphia: Temple University Press, 2012.

Atasha and Anna miss their home desperately, and they are unable to understand why their father sold them to the Borefsky Brothers Circus. As they learn to negotiate their inseparability, they fall in love with different men—one of them married—and Atasha eventually falls in love with Shanghai, a fire-breathing dwarf. The ‘twist’ of the novel, for which Frazze received an Honorable Mention for the Astraea Lesbian Foundation for Justice 2005 Emerging Lesbian Writer's Fund, is that one of the twins is a lesbian. This theme of sexual identity is a topic that I address extensively in chapter five.

Other novels⁶ include *The Implacable Order of Things* (2008) by Portuguese novelist Jose Luis Peixoto, which won the Saramago Literary Award. Among the various characters are twins conjoined at the little finger. *Human Oddities* (2005), by Noria Jablonski, is a collection of short stories that begin and end with stories about conjoined twins, one of which, “Pam Calls her Mother on Five-Cent Sundays”, is reminiscent of real-life conjoined twins, Daisy and Violet Hilton. *Monster: Oil on Canvas* (2010) by Russian-born Dmitry Zlotzky is a fairytale in which conjoined twins, Alex and Alex, set about to find the only doctor who can separate them. During their quest, they fall in love with Love, Hope, and Faith, but none of these relationships can be sustained. *Freak of Nature* (2007) by Phil Whitaker, a British author and physician, is the story of conjoined twins, John and Mike McDonald, who are completely opposite in terms of their personalities, goals, and lifestyles. To complicate matters further, John is in love with Mike's wife. The ‘twist’ of the novel comes when an MRI reveals that the ‘twins’ have only one head—and John is nothing more than a manifestation of Mike's inner turmoil. Finally, *Ludmila's Broken English* (2006), by award-winning novelist DBC Pierre, features UK-born conjoined twins, Bunny and Blair Heath, who have been separated (at age 33) prior to the main action of the novel. They share the plotline with Ludmila Derev, who sets out to save her poor family in the former Soviet Republic.

In addition, there are several novels that could be classified as young adult/adolescent fiction: *Love Will Tear Us Apart* (2005) by Tara McCarthy; *The Secret Twin* (2007) by Denise Gosliner Orenstein; and *Harry and Ida Swap Teeth*

⁶ In addition to the novels that I mention here, *Brothers One: Conjoined Twins* (2003) by David Valley is also about conjoined twins. I have not, however, been able to locate a copy.

(2003) by Stephen Jones. A number of comics have also featured conjoined twins: *God's Love is Like a Conjoined Twin* (2010) by Dean Rankine and *Evelyn Evelyn* (2011) based on the music album of the same title by musicians and storytellers Amanda Palmer and Jason Webley.

In addition to literary fiction, a number of recent films have featured conjoined twins. While Julianna de Nooy writes about the use of conjoined twin brothers as prominent figures in 1980s and 1990s horror films, the films that emerged at the close of the 1990s moved against this convention. *Twins Falls Idaho* (1999), for example, is a film about twins, Blake (Mark Polish) and Francis (Michael Polish) Falls, who must not only renegotiate their relationship when a love interest enters their lives, but must also face the physical and psychological implications of separation when Francis becomes ill. In her discussion of this film, which was referred to by its tagline as a “different kind of love story”, de Nooy claims that it “attempts to [...] rearticulate the twin relation” (2005: 81) and deflect the “pattern [that is] the product of a particular conjunction of topos (conjoined twins), gender (male), genre (body horror) and era (post-1980)” (ibid). This shift away from the pattern that de Nooy describes is illustrative of a gradual opening in the representations of conjoined twins, which this thesis examines.

Stuck on You (2003), is a comedy about conjoined twins Bob (Matt Damon) and Walt (Greg Kinnear) Tenor who move to Hollywood to pursue Walt's acting dreams. When both ultimately become famous, Bob brings his Chinese pen-pal girlfriend, May, to the United States. Since she does not know beforehand that Bob is a conjoined twin, she leaves suddenly when she discovers him ‘in bed’ with another man. Aware of Bob's unhappiness when he loses May, Walt convinces him to agree to separation so that he can pursue and marry her. The surgery is a success; Bob renews his relationship with May; and the twins begin to lead separate lives. At the very least, the film offers viewers something beyond the typical horror film that de Nooy sees as characteristic of the 80s and 90s. In addition, it draws on the social model of disability, as Niall Richardson argues in *Transgressive Bodies: Representations in Film and Culture* (2010). The social model of disability, which is explored in more detail in chapter three, presents conjoinment as more than a physical problem that can be solved through surgery.

The ending of the film—with its successful separation surgery—is highly ambivalent and can be read in a variety of ways. According to Richardson, it:

fails to pursue the full potential of this situation by returning to the obligatory 'happy ending' in relation to disability narratives. [...] Although the film demonstrates that they suffer some difficulties in living apart, by the films conclusion it is apparent that this separation was 'for the best' as both can now live 'normal' happy lives. (191)

The surgery allows the twins to find happiness on their own, as Richardson argues, but it also presents the separation as a greater hindrance to their lives. Once they are separated, Walt loses his job in Hollywood, and Bob—even though he 'wins back the girl'—returns to his job in Oak Bluffs, but he can no longer function without Walt. While the restaurant that the twins worked in could once boast being able to deliver food in less than three minutes, it can no longer sustain this promise without the twins and their perfect synchronization. The twins—each in their own way—are therefore paralyzed; they cannot function wholly without each other. They choose to recreate their conjoinment by fastening themselves together in clothing fashioned with Velcro.

Finally, *Brothers of the Head* (2006), is a mock-documentary ('mockumentary') adapted from a novel of the same title by Brian Aldiss, featuring fictional conjoined British twins, Tom (Harry Treadaway) and Barry (Luke Treadaway) Howe, who are turned into rock stars by a greedy manager who purchases them from their family. The movie tagline, which reads "For some people...Rock & Roll was always a freak show", alludes to the connections between celebrity culture and the freak show, as well as 'other' bodies and their representation. The music industry representatives who stage the band's performances use the twins' physical difference to entice the audience, and the brothers become celebrities for their musical talents, but also because of their unique physicality. Eventually, as they continue to gain fame, a young female music journalist follows their band, eventually falling in love with Tom. Similar to the situation presented in *Twin Falls Idaho* and *Stuck on You*, the romantic interest inserts herself into the dynamic, thereby leading to tensions between the twins.

Television has also witnessed a rise in the number of storylines involving conjoined twins. In the United States, conjoined twin stories have been featured twice on *Grey's Anatomy* in episodes titled, "Don't Stand So Close to Me" (2006)

and “This Magic Moment” (2012). The former deals with adult conjoined twins, Jake and Peter, who have come to Seattle Grace Hospital for separation because one of the twins wants to pursue a more ‘normal’ relationship with his girlfriend, while the latter details the preparation for and surgical separation of newborn conjoined twins. Adult conjoined twins, played by real-life conjoined sisters, Reba⁷ and Lori Schappell, have also been featured on *Nip/Tuck*, a detailed analysis of which is included in chapter two. Finally, the hit-series *Bones* featured an episode, “Double Trouble in the Panhandle” (2009), in which the two primary detectives go undercover in a travelling circus to learn more about the death of conjoined female jugglers who were found at the border of Texas and Oklahoma.

Why Conjoined Twins and Why Now?

This thesis responds to the heightened interest in conjoinment by considering the representation of conjoined twins primarily in American culture around and since the turn of the twenty-first century. It is impossible to explain the precise reason why the figure of conjoined twins has become more and more popular during this time period. However, representations of conjoined twins respond to the cultural anxieties outlined above and feed into an ever-increasing fascination with the body. According to Grosz, the body is “a point from which to rethink the opposition between the inside and the outside, the public and the private, the self and other, and all the other binary pairs associated with mind/body opposition” (1994: 21). Bearing this in mind, the figure of conjoined twins provides a means of opening a critical dialogue about the phantom boundaries between oppositional pairs—self and other, mind and body, and normal and abnormal, to name but a few.

Representations of conjoined twins often rehearse these debates about the body through the focus on separation surgery. The separation of conjoined twins regularly becomes a global media event because doctors are testing the limits of technology and surgical skills, so just as technology provides the tools to achieve a normative body, so too does it provide a means through which surgical alteration

⁷ Reba was born Dori Schappell, but she changed her name to Reba when she began her career as a country singer. Since 2007, she has preferred to be called ‘George’. I have chosen to refer to her as Reba since, in most of her public appearances, which are the focus of my project, she still uses that name.

can be presented to viewers beyond the immediate medical setting. In doing so, such representations of conjoinment feed into the current popular interest in technological advances that have made possible many alterations to the body, including prosthetics, reconstructive surgery, and even sexual reassignment surgery. As Niall Richardson explains, we are living in a time in which the manipulation of the body is a common theme in popular culture: “Turn on the television any night of the week and we are able to find programmes devoted to the body; or more explicitly the regulation and discipline of the body so that it conforms to acceptable standards of beauty” (2010: 1).

Cosmetic surgeries, which have seen a rapid increase over the past few decades, are a means through which the body can be either maintained or upgraded, or in some cases, completely reconfigured. In *Medicine Unbound: The Human Body and the Limits of Medical Intervention* (1994), Robert Blank asserts that “[W]e in effect have medicalized physical appearance” (6): “We strive for perfect bodies through chemicals and cosmetic surgery, for enhanced mental powers through ‘smart drugs’, and for replacement of worn out body parts. In all these cases, technology becomes the perceived liberator from human limitations” (ibid: 4). Additionally, technology, as well as the physicians trained to use it, become the ‘perceived liberators’ from a variety of physical differences. Bernadette Wegenstein’s term ‘cosmetic gaze’ describes how the body comes to be seen in terms of potential. Through the cosmetic gaze, the surgical cut emerges as a tool of transformation:

The *cosmetic gaze* is [...] transfixed by a plane of potential that lies below the skin and is accessible only via the action of cutting (with old-fashioned scalpels or the less invasive ways enabled by digital technology). This plane is far from a mere voluntary fantasy. It is always a platform for projections that are limited by a special moment in a body’s history when the self was perceived as truly “good and beautiful.” The cosmetic gaze thus perceives all bodies in light of some potentially transformative completion, while at the same time transfixing that potentiality on the phantom remnant of a “true” self that is fixed in time. [...] The gaze carves out (to use one of the sculptural metaphors of the cosmetic surgery industry) what in the body obscures its perfection and leaves behind only what is beautiful and meant to be seen by others. (2012: ix; her emphasis)

For Wegenstein, the body is the material of potential, so it is here that beauty can be realized or restored.

The cosmetic gaze is applicable to bodies that are eligible for small ‘repairs’ or ‘restorations’; there is, as Wegenstein says, an ever-present desire to return to the ‘true self’—a self that once was and can be re-imagined through surgery. The cosmetic gaze in cosmetic surgeries can be compared to the medical gaze in ‘normalizing’ surgeries that aim to repair bodies that are viewed as disabled or anomalous. In these cases, the idea of potential is still a powerful force, but rather than returning to a past true self, the body is reconfigured to *become* an ideal self that was inaccessible before. These bodies do not *return* to a previous state of beauty and perfection; they are reborn through surgery in the elusive image of what they *should have* been. What the cosmetic and medical gaze share is that surgery becomes the tool through which social norms and ideals are inscribed directly onto the body.

To understand how such ideals figure in representations of conjoined twins, it is important to offer some background information on the various debates about the medical and ethical treatment of conjoined twins. At birth, conjoined twins are immediately implicated in the process of normalization. The medical imperative to separate, which is caught up in the desire to give them the bodies that they *should* have had, immediately engraves potential onto the material of the body. One of the foremost concerns regarding conjoined twins, and others with different bodies that are deemed ‘inappropriate’, is their ability to lead so-called ‘normal’ lives and assimilate successfully into their respective societies. In the BBC2 documentary, *Conjoined Twins* (2000), Dr. Röde, the lead surgeon separating Tanzanian twins, Stella and Esther Alphonse, states

They’re very cuddly at the present moment and everyone likes them, but once they’re 10 years old how will they go to school. They will always have to share whatever they do. That is defecation they will share, it’s a practical example, they will share mobility, they will share sleeping, they will share the ups and downs of life [...]. I think for, for the rest of the world it’s unacceptable to live in close proximity to somebody else if the chance had been for a successful separation earlier on. You cannot go through [...] in this, in this situation. You will be outcast, you will become a, a monster, you will become a curiosity, you will become a showpiece. (transcript)

His concerns allude to quality of life, which he clearly believes is out of the realm of possibility for people whose bodies do not conform to the normative ideal of a clearly defined single and autonomous body.

There is, however, an alternative to the outlook offered by Dr. Röde. Alice Dreger argues that being born conjoined mirrors the experience of being born into a single body: "Conjoined twins tend to grow into a body that they're born with, the same way the rest of us do and so they're born into this body joined and they will develop an understanding of their lives as joined" (qtd. in *Conjoined Twins*). For Dreger, anatomical difference (including conjoinment) is a social construction, best treated by "chang[ing] minds instead of bodies (2004: 149). The same is true for Rosemarie Garland-Thomson, who points out that "the ways that bodies interact with the socially engineered environment and conform to social expectations determine the varying degrees of disability or able-bodiedness, of extra-ordinariness or ordinariness" (1997: 7). Both claim that it is society's normative expectations, sustained by its "exclusionary discourse" (ibid: 6), that constructs barriers and limits the ability of "physically extraordinary figure[s]" to become productive, appreciated members of society (ibid: 5). Bodily difference is not the entire problem; often it is the reaction to that material difference that amounts to a crisis for society and, by extension, the differently-bodied individual. This is a debate that I take up in subsequent chapters.

These alternate views of conjoinment as either a medical or a social problem (or both) are discussed at length in the following chapters. For the purposes of this introduction it is important to point out that cultural representations of conjoined twins vary in their response to conjoinment. Representations can reinforce ideals of physical 'normalcy', but they can also make the reader or viewer aware of the process through which certain norms and ideals are naturalized in the first place, thus potentially opening up the possibility of critique. More often than not, representations of conjoinment are both restrictive and subversive, as the discussion in the following chapters will show. Overall, one of the aims of this thesis is to explore the different ways in which representations of conjoinment relate to social and cultural ideologies regarding subjectivity and physical difference.

Situating Conjoined Twins

My thesis begins by tracing the evolution of 'other' bodies from monsters to freaks, and to patients. It gives special consideration to the unique and paradoxical situation of the freak show as a historical site and a conceptual space, offering the necessary background for the ensuing discussion of contemporary representations and constructions of conjoined twins. After all, "[f]reak discourse did not vanish with the shows, but proliferated into a variety of contemporary discourses that still allude to its premises" and directly impact contemporary discourses of conjoined twins (Garland-Thomson 1996: 13). Objectification, subjectivity, exploitation, exposition, entertainment, and public versus private space are just a few of the topical issues that are not only central to the freak show, but also prevalent in twenty-first-century representations of conjoined twins. An examination of the process through which physically different bodies were constructed throughout different historical periods is a means to trace both continuity and change and offer the necessary background against which present-day representations of conjoined twins can be read.

Once unusual bodies displayed in freak shows were situated in the medical sphere, freaks became patients, yet certain dynamics of the freak show remained and became fixed in medical discourse and practices, as well as in their representations in popular culture. Through an analysis of two medical documentaries of conjoined twins, as well as an episode of the popular American drama, *Nip/Tuck*, chapter two examines medical discourse as a strategy for producing and affirming social norms and marking 'other' bodies as deviant. It looks specifically at the ways in which medical documentaries uphold the medical model of disability—the view that non-conforming bodies must be 'repaired' for the sake of normalcy. The chapter is concerned with the way in which the physically different body is reshaped through a constant anticipation of the desired effect and future result of 'normalcy'. It considers how medical discourse is implicated in the idea of a 'normal' body, but it also examines the ways in which the figure of conjoined twins opens and subverts the very idea of 'normalcy', thus pointing to the need for a more expansive view of disability.

Other contemporary filmic representations of conjoined twins have employed alternative views that place increasing emphasis on non-pathological constructions of the body. Chapter three focuses on three documentaries that promote a social model of disability, which separates impairment from disability, positioning disability as a social construct rather than a biological problem. These narratives present an alternate means of constructing 'normalcy'; the emphasis shifts away from the body of conjoined twins as an object to be observed and surgically acted upon and towards the conjoined twins as subjects who negotiate their relationship with each other, their shared body, and greater society. 'Normalcy' is no longer defined by the medical gaze, but rather comes to be understood through an engagement with the individual and his or her social context. The representations employed in these documentaries engage with ideologies of the body, adding to a more diverse range of images that have the potential to challenge negative views of the physically different body, but, as will be argued, they too promote a limited view of disability that must be problematized.

Chapter four demonstrates how literary writing critically engages with both models of disability, arguing that disability studies can be significantly enriched by a consideration of contemporary fictional representations of conjoined twins. Rather than settle on either a medical or social model of disability, the two novels that I discuss in this chapter, *The Girls* (2007) by Lori Lansens and *Cutting for Stone* (2010) by Abraham Verghese, expose the inherent risk in upholding the strict dichotomy between impairment and disability. Rather, these novels show how the figure of conjoined twins demonstrates the need to bring the body back into discussions of disability and promote an understanding of disability as a category of identity that is shaped simultaneously by the individual body and the meaning that the body has come to bear within a larger social and communal context. In their treatment of disability as both biological and social, these novels mirror contemporary debates in disability studies that seek to bring together various aspects of the medical and the social models of disability.

Chapter five moves beyond disability studies, but maintains its connection to topical issues surrounding the body, by examining how literary representations

of conjoinment, *First Person Plural* (2007) by Andrew Beierle and *Half Life* (2007) by Shelley Jackson, deal with sexual dissidence and sexual identity formation. Sexuality and conjoinment are similar in that they raise questions of identity formation; the identity of the conjoined twin is at stake not only because of his or her conjoinment, but also specifically because of her uneasy position as a sexual subject. This chapter draws on recent critical work in the fields of queer theory and sexuality studies, which has raised increased awareness of the intimate relationship between time and sexuality. This work has shown that normative figurations of time, primarily linearity, teleology and futurity, contribute to the naturalization of certain forms of sexuality. This chapter shows that the same normative timelines are imposed on the life course of conjoined twins, allowing for a nuanced understanding of how conjoinment relates to questions of sexual and gender identity.

Cultural Studies: The Approach

As an interdisciplinary project, this thesis works across genres and interrelated topical issues to open up, understand, critique, and potentially transform categories of difference. Because it is about *all* of these issues and ideas at once; because it is about interrogating the multi-layered process through which something comes to be seen as ‘natural’ and the relations of power that are engaged with and within that process; because it “encompass[es] different positions and trajectories in specific contexts, addressing many questions, drawing nourishment from multiple roots [...]”, the approach is best described as cultural studies, or even more specifically, representation studies (Grossberg, Nelson, and Trechler 1992:3).

My approach to this thesis reflects the argument I make about the project as a whole: choosing to categorize—to label something as entirely ‘this’ or ‘that’—is both reductive and unproductive. This project is not only about genre, and it openly “rejects the exclusive equation of culture with high culture” (ibid: 4). This is the reason I have chosen to examine a range of fiction, film, documentary, and television. Neither is it just about disability; in chapter five, as I mention in the previous section of this introduction, it resituates the discussion of the body,

branching into sexuality. And though I examine the representation of conjoined twins specifically, this thesis is a commentary on all difference and an attempt to alert us to the effects of representation across a range of texts, spaces, and periods of time—a point that I make clear in my discussion of Stuart Hall and representation studies earlier in this introduction.

Social and political engagement has become almost an expectation of work done in Cultural Studies. According to Grossberg, Nelson, and Trechler, “There is a kind of double articulation of culture in cultural studies, where ‘culture’ is simultaneously the ground on which analysis proceeds, the object of study, and the site of political critique and intervention” (ibid: 5). In other words, theoretical knowledge has a political force that cultural studies, as an academic discipline, encourages. In “What’s the Matter with Cultural Studies?”, Michael Bérubé ultimately concludes that “cultural studies’ understanding of hegemony is a form of understanding with great explanatory power—that is to say, a form of understanding that actually works” (2009). I am choosing to see Bérubé’s use of ‘works’ in two different, but equally important ways here. Cultural studies ‘works’ in the sense that it is effective in terms of providing an account, but it also ‘works’ in the sense of exerting influence. To that end, cultural studies scholars are active participants in processes of political transformation. These are the benefits of such an approach.

There are potential limitations to a cultural studies approach as well. Because of the range of this project, the discussion might at times appear to gloss over some of the finer nuances of each debate or topic covered. For this reason, it has been important to define clearly the particular terrain of each issue discussed (e.g. temporality with regard to sexuality) and address questions of genre as they arise. Pursuing work that is beyond any clearly defined discipline can be problematic, especially in terms of readers’ expectations. The impulse to try and categorize this project—to make it ‘fit’ into a discipline—is understandable, however, to do so would be to diminish its potential to interrogate fully how processes of representation work across different rhetorical and cultural spaces.

A Final Note

Alice Dreger's *One of Us* (2004) is the only extensive recent study of conjoined twins from a cultural and historical perspective. It has been an invaluable source of information and instrumental in my decision to examine the cultural and literary representation of conjoined twins. While Dreger calls into question the ethics of separation surgery for conjoined children and shows how those with unusual anatomies unsettle ideas of 'normalcy', my project examines the contemporary representation of conjoined twins in different genres (novels, television, and documentary) and illustrates the extent to which conjoinment is used as a trope to uphold or subvert traditionally held ideas about subjectivity, and physical difference. In addition to Dreger, I am particularly indebted to the work of Rosemarie Garland-Thomson, who discusses the ways in which disabled bodies, much like other bodies that are commonly thought of as 'other', have been constructed by culture. In *Extraordinary Bodies: Figuring Physical Disability in American Literature and Culture* (1997), Garland-Thomson turns to literature (among other things) as part of her political agenda of opening up a dialogue within the humanities regarding the construction of disability. As an examination of representation, my project is primarily positioned within literary and cultural studies, but it is heavily influenced by the debates opened up by scholars like Dreger and Garland-Thomson and also seeks to contribute to the burgeoning fields of disability studies and medical humanities.

Dreger and Garland-Thomson's emphasis on ethical concerns also raises awareness of the inherent risks in choosing to write about conjoined twins. First, I am not a conjoined twin, nor do I know personally any conjoined twins. I was therefore initially reluctant to proceed with a thesis that examined the representations of a group of people whose experiences I do not share. I was comforted and inspired to proceed, however, when I read Tom Shakespeare's concluding remarks in *Disability Rights and Wrongs* (2006):

The idea that having an impairment is vital to understanding impairment is dangerously essentialist. The skills and knowledge of an experienced and sensitive researcher, disabled or non-disabled, are required to develop an appropriate account. Non-disabled researchers may be able to connect their own experiences of disempowerment or marginalisation [...] to attain insight into the barriers experienced by disabled people. (195)

I have tried to remain sensitive and respectful throughout this project, and while I discuss representations of conjoined twins in a variety of contemporary texts, I make no judgments about what choices are made in terms of their medical care. Especially with regard to chapter two, I would like to state emphatically that my goal is not to judge the decisions made by families and doctors to separate conjoined twins nor to make any value statement about their motives. I wish only to examine and evaluate the ways in which these cases are translated through the filmic medium—represented—in a way that directly reinforces an ideology of ‘normalcy’.

Second, I was hesitant to use conjoined twins as a means of discussing contemporary debates in disability studies because I have found no concrete evidence that any conjoined twins view themselves as disabled. In fact, it is limiting to assume that anyone with a body outside of the norm sees himself or herself as disabled. With regard to this caveat, I default to Dreger, who states,

Many unusual anatomies are treated almost exactly like traditional disabilities. That is, a physical difference is *treated* as a physical defect; [...] the subject’s body instead of the body-environment interaction is treated as the fundamental problem; intense debilitating, silencing shame is attributed where none ought to be; and basic rights—to employment, self-determination, education, marriage—are denied by others, who assume that these rights are the preserve of people with typical bodies. (2004: 147; my emphasis)

Her explanation, which emphasizes social construction and treatment rather than personal self-understanding, allowed me to view conjoinment in terms of disability. Moreover, disability studies offered me the most useful conceptual framework to address and explore the numerous questions raised by contemporary representations of conjoined twins.

It is also important to outline briefly why I have chosen to use the term ‘disabled person’, or simply ‘disabled’, rather than ‘person with disability’. In *Claiming Disability: Knowledge and Identity* (1998), Simi Linton examines the origin and evolution of a variety of positive and negative terms and phrases that have been used to describe disabled people. She concludes that ‘disabled’, as a term, “has become a marker of the identity that the individual and group wish to highlight and call attention to” (13). For Linton, who is herself disabled, to refer to

someone as a ‘disabled person’ places him or her within a community; it keeps ‘disability’ in a central position as part of a person’s identity rather than “maintaining disability as a secondary characteristic” (ibid). In *Autism* (2012), Stuart Murray presents an equally compelling case. In his examination of autism, he contends that the phrase ‘person with autism’ “suggests—too easily—that autism might be removed from the person, as if to have autism is to have a cold or some disease” (xiv). Both of these explanations are important in the context of this thesis, since I attempt to offer a more nuanced understanding of disability as always both biologically and socially constructed. I have therefore chosen to use ‘disabled’ to highlight disability as an important component of identity.

Finally, it is always problematic to add to the corpus of work of which you yourself are openly critical. I recognize that even this thesis is a *representation* of conjoined twins, and therefore risks reinforcing reductive images of physical difference and ‘normalcy’. What I hope, however, is that my work illustrates the potential of the figure of conjoined twins to “[keep] representation open” (Hall 2005: 22) and produce “new kinds of knowledges, [...] new kinds of subjectivities, [...] and new dimensions of meaning which have not been foreclosed by the systems of power which are in operation” (ibid).

Chapter 1:

Monsters, Freaks, and Patients: Tracing the Unusual Body Through History

The surge of interest in the figure of conjoined twins over the past decade shows that it speaks specifically to contemporary concerns. To fully understand the role of conjoined twins in contemporary culture, it is important to trace how the unusual body came to be understood through history. This chapter offers an overview of the different cultural changes that have led the unusual body to move from its position as monster to freak in the nineteenth century and then to patient in the later twentieth century. In doing so, the discussion highlights processes of change, but it also explores which aspects of the relation to unusual bodies, like those of conjoined twins, have remained consistent. Tracing both continuity and change during different historical periods offers the necessary background against which present-day representations of conjoined twins can be read. The cultural demand for the delineation of the self, as well as the need for stable binaries of self and other, and human and non-human, for instance, runs through the different historical periods discussed. At the same time, the unusual body in its various figurations has continuously served to challenge and undermine these distinctions and it is partly due to this function that conjoined twins continue to be highly relevant in the present day. By focusing on the freak show in particular, the chapter offers the necessary historical background to understand how representations of otherness serve to both stabilize and challenge ideals of 'normalcy' and selfhood.

Unusual bodies have served throughout history as the sites upon which contemporary anxieties were written. The types of bodies labelled 'abnormal'—and the meanings of those bodies—have constantly shifted, never inhabiting any position for too long. Until the Age of Enlightenment, 'monsters' were interpreted as signs of divinity, punishment for sins committed, physical manifestations of wrath, or even signs of the angelic. They were prodigies or miracles, inspiring anxiety or respect depending on the context of their appearance. During the sixteenth and seventeenth centuries, they were interpreted as religious omens or signs of divine communication, and the fascination that people had for them could be seen in elaborate prodigy books printed for society's educated elite as well as the broadsides and pamphlets that were mass printed for the general public. In

addition, various philosophical texts during this period confirmed the dominant belief in the link between monsters and the divine. In the “Introduction” (1982) to her translation of Ambroise Paré’s *On Monsters and Marvels*, a highly influential sixteenth-century text, Janis Pallister explains, “Paré’s frequent referral of the mysteries of disease and healing to an omnipotent deity [...] is common among Renaissance surgeons who were, for the most part, a fairly devout group, whether Protestant (as Paré may have been) or Catholic” (xv-xvi). This is immediately obvious in the case of Paré, who begins his treatise with a list of the causes of monsters: “The first is the glory of God. The second, his wrath” (ibid: 3). The fact that he assigns both glory and wrath to monsters points to society’s complex relationship with monsters; they are to be respected and feared. In “Wondrous Monsters: Representing Conjoined Twins in Early Sixteenth-Century German Broadsheets” (2005), Jennifer Spinks confirms this complexity. While she admits that monstrous births were usually considered god’s punishment for sin, she examines three publications on conjoined twins born around 1500, which prove the opposite, “demonstrat[ing] how children perceived as monstrous could [...] be viewed in a sympathetic light, interpreted as positive political omens, and even represented in the guise of the infant Christ” (77). This demonstrates that the social response to monsters has tended to be complex and contradictory.

By the close of the seventeenth century, natural philosophers had begun to seek scientific rather than religious or metaphysical explanations for abnormal bodies and their origins. While they suspected that monstrous births were the result of natural causes, they did not yet have the tools or knowledge to substantiate their hypotheses. With the publication of his series of public lectures, *Discours Anatomiques* (1675), French physician Guillaume Lamy named natural order as the cause of normal, as well as monstrous, births. This hypothesis necessarily led to anxieties over what (or who) was to blame for monstrous births and how these could be explained within a rational and scientific framework. The conflation of science and medicine that occurred in the following centuries would provide more authoritative theories.

The eighteenth century marked a significant, albeit gradual, shift in the treatment of monsters due to the rise of scientific knowledge, which sought to deliver rational explanations for phenomena that were previously understood as

supernatural. In turn, monsters' "power to inspire terror, awe, wonder, and divination was being eroded by science, which sought to classify and master rather than revere the extraordinary body" (Garland-Thomson 1997: 57). On the one hand, science established clear boundaries between the human and the monstrous. Philip K. Wilson, for instance, argues in "Eighteenth-Century 'Monsters' and Nineteenth-Century 'Freaks': Reading the Maternally Marked Child" (2002) that Carl Linnaeus' classification of *Homo monstrous* as distinct from *Homo sapiens* in 1758 "stigmatized deviance because it distinctly distanced monsters from humans, treating them as a separate species" (8). On the other hand, however, one must consider the changing perception in the period as a whole, which led to a blurring of the borders between the human and the monster. Wilson points to the paradox of Linnaeus' system, which not only differentiated clearly between humans and monsters, but also "emphasized the interrelatedness of these different species by focusing upon particular blendings or hybridizations of characteristics" (ibid). This fusion points more generally to one of the most pertinent outcomes of this shifting conception of the 'abnormal' body: the destabilization of the human/monster binary. As soon as monsters could no longer be safely delegated to the sphere of the supernatural, they had to be accounted for as phenomena subject to the same natural rules and laws governing human life. This shift in the understanding of the maternal body illustrate how the borders between the human and the monstrous were unsettled in a bid to provide scientific explanations for physical deformities.

Maternal Impression

The idea of maternal impression, which became more prevalent in eighteenth century medical and scientific debates, established a link between the human body and the monstrous one. According to Rosi Braidotti, the "'imagination' hypothesis" (1999: 296), as she refers to it, "attributes to the mother the capacity to undo the living capital she is carrying in her womb; the power of her imagination is such that she can actually kill or deform her creation" (ibid). The very fact that physical deformity could be linked to the mother's body rather than to external metaphysical or supernatural forces is indicative of the shift towards

an understanding of the unstable borders between the human and the monstrous. The maternal body not only came to bear the responsibility for monstrous births; it was also aligned with the monstrous itself, so that the human/monster binary was unsettled. As Braidotti states:

[T]he mother's body seems to be in a position structurally analogous to the classical monster: it is caught in a deep contradiction which splits within itself. The female, pregnant body is posited *both* as a protective filter and as a conductor or highly sensitive conveyor of impressions, shocks and emotions. It is both a 'neutral' and somewhat 'electric' body. There is an insidious assimilation of the pregnant woman to be an unstable, potentially sick subject, vulnerable to uncontrollable emotions. (ibid: 299; her emphasis)

Maternal impression places the course of the 'normal' development of an unborn child not in the hands of a divine power, but in the hands of the mother. Because the mother—and women overall—are stereotypically seen as weak, whimsical and non-rational, the idea that the mother can be responsible for a monstrous birth furthers the fears concerning the corrosion of the border between the monstrous and the human.

Doctors and philosophers alike sought to rule out sporadic factors completely as a means of disciplining uncontrollable aspects of human development. In his 1749 "Lettre sur les aveugles à l'usage de ceux qui voient" ("Letter on the Blind"), French philosopher, Denis Diderot, postulated a strictly mechanical (anti-spontaneous and law-governed) view of nature and development, proposing an underdeveloped theory of natural variation that directly attacked the notion of divine intervention. Further, as one of the contributors to *L'Encyclopédie*, Diderot, according to Braidotti, goes to great lengths to dismiss the imagination of the mother as a contributor to monstrous births because imagination proves "an obstacle to true knowledge" (1999: 298). Braidotti states that while *L'Encyclopédie* "argue[s] that the imagination is an important faculty which moves us all, especially pregnant women, [...] there is no direct link between the movements of the imagination and physiological processes" (ibid).

Although Diderot and his contemporaries showed little tolerance for an understanding of development that viewed the mother as an active agent of potentially uncontrollable development, debate still continued in both popular

and medical texts, as Wilson discusses. Two London physicians, Daniel Turner and James Blondel, rehearsed these arguments in public pamphlets, Turner

accept[ing] the long-standing belief in the power of the maternal imagination, whereas Blondel refuted his view, drawing upon logical (*post hoc ergo propter hoc*) argument and anatomical evidence. One perennial problem, well articulated by Blondel, was that physicians, midwives, and mothers typically resorted to an explanation of the power of the maternal imagination *after* noticing some irregularity on a child's body. Blondel also noted that women frequently experienced longings and frights during their pregnancies without producing marked children. (2002: 5; his emphasis).

These debates highlight the division on maternal impression that lasted well throughout the eighteenth century and into the nineteenth century.

Nineteenth Century & Teratology:

Professor Etienne Geoffrey Saint-Hilaire was influential in changing the trajectory of the meaning of 'monster'. In his comparative anatomical studies, which he published in 1822 as *Philosophie anatomique. Des Monstruosités humaines, ouvrage contenant une classification des monsters*, he constructed a new system that classified monsters according to their distinct characteristics, proposing that a sudden disruption of normal foetal development was the cause of morphological deformities. His son Isidore, a zoologist and embryologist, continued to develop his father's work, articulating in *Histoire générale et particulière des anomalies de l'organisation chez l'homme et les animaux* (1837) an even more elaborate system of classification that considered a greater variety of physical deformities. Together, father and son pioneered the scientific study of monsters, Teratology, which marked a significant step in the rationalization of the monster. By artificially generating monstrosities in animal embryos, the two developed scientific laws that governed the production of monsters, declaring authoritatively that divine intervention was not responsible for one-off phenomena that sometimes occurred as a result of natural human processes. It was no longer divine interference that caused monstrosities, but abnormal foetal development, which was part of a natural order that could be scientifically and rationally explained.

Teratology further removed the monster from its position 'out there', far distanced from humanity, to its position as precariously human. Moreover, the scientific study of monsters helped to propel bodies marked by inexplicable difference into the realm of scientific and human possibility. As soon as monsters were assimilated into the realm of the possible, two changes occurred. First, the precarious process of identifying with the monster could begin to overcome the process of objectifying the monster. Monsters were objectified as specimens and freaks (a point to which I will return later), but Teratology also made identification possible, as it placed the monster in the dual, conflicting role of "Same and Other. The monster is neither a total stranger nor completely familiar; s/he exists in an in-between zone" (Braidotti 1999: 292). The fusion of 'normal' and monstrous began to destabilize and make problematic the entire concept of normality. To transgress the binary between human and monster, and hint at the 'in-between'—the hybrid body that does not remain or cannot be bordered—is to undermine and reveal its arbitrariness. If a body can be simultaneously self and other, human and monstrous, it follows that the radical differentiation between both kinds of bodies ultimately does not make sense, as they are not entirely different after all.

Second, scientific research began to draw attention to the fact that individual development was liable to deviations from the norm, as it was governed by chance. To understand foetal development more fully, scientists like French zoologist Camille Dareste set out almost thirty years after Geoffrey Saint-Hilaire to deliberately create monsters. Influenced by the work of the Hilaires, Dareste artificially produced deformities in chicken embryos to gain a better understanding of the genesis of monstrosity. Ultimately, he would write two complementary pamphlets, one in 1862 and the other in 1863, which would detail the results of those experiments. In a letter to Charles Darwin, along with a copy of the second pamphlet, Dareste describes his own dissatisfaction with the "fixity of species" ("letter to Darwin", 703), a belief commonly accepted by naturalists, and he expresses deep gratitude for *The Origins of Species* (1859), which "caused a light to shine in the midst of darkness, by showing [him] where to look for the guiding principle that hitherto had been lacking in [his] reflections on the nature of species" (Dareste, "letter to Darwin", 703). As an evolutionist, Darwin would

have had a keen interest in embryological research because he believed that ontology, the development of the individual (from conception to fully formed human), mirrored the development of the species, phylogeny. Darwin would later cite Dareste's experiments in *The Variation of Animals and Plants under Domestication* (1868) "to illustrate the point that external conditions could be the direct cause of modifications in the structure of organisms" (Darwin, "letter to Dareste" 704).

In their respective works, Darwin and Dareste both dealt with the implications of the arbitrariness of development—the fact that 'normal' development was not 'fixed' and could always deviate from its path. According to Darwin,

The old argument from design in Nature, as given by Paley, which formerly seemed to me so conclusive, fails, now that the law of natural selection has been discovered. We can no longer argue that, for instance, the beautiful hinge of a bivalve shell must have been made by an intelligent being, like the hinge of a door by man. There seems to be no more design in the variability of organic beings, and in the action of natural selection, than in the course which the wind blows. (Darwin 1887: 309)

This lack of design as well as the unpredictability of human development is also mentioned in Drs George M. Gould and Walter L. Pyle's *Anomalies and Curiosities of Medicine* (1896), a compilation of unusual medical observations ranging from Hippocrates to the mid nineteenth century:

In monstrosities [...], we seem to catch forbidden sight of the secret work-room of Nature, and drag out into the light the evidences of her clumsiness, and proofs of her lapses of skill,—evidences and proofs, moreover, that tell us much of the methods and means used by the vital artisan of Life,—the loom, and even the silent weaver at work upon the mysterious garment of corporeality. (1)

Their metaphor of Nature as an imperfect weaver fashioning the 'garment of corporeality' suggests infinite bodily variations and points to the link between monstrosities and 'normal' humans. In other words, natural development is random and prone to mistakes, which diminishes the assumed difference between the monstrous and the human.

These advances in science led to widespread criticism of maternal impression as an explanation for monstrous births. Nevertheless, the theory remained popular in the nineteenth century and appeared regularly in both

popular and medical texts. In Joseph Merrick's (the "Elephant Man") penny pamphlet, which is discussed later in this chapter, his deformity is attributed to a fright his mother suffered. Chang and Eng Bunker, the 'original' Siamese twins, were also banned from appearing in France at the height of their popularity because authorities were concerned about the impact that their appearance might have on pregnant women. In medical texts as late as 1875, Assistant Physician to Britain's Hospital for Women, Dr. E. Holland, warned pregnant women that their mental state could have a material and psychic effect on their unborn children:

Ever treasure in your mind that the mental state of your child will be largely determined by the mental state you yourself observe during the bearing of it; and that its physical vigour will be materially influenced thereby. Under these circumstances you will appreciate the necessity of attending to your mental training as well as your bodily health; and as the two are intimately associated, moderating and influencing each other every hour in the day, I will briefly explain to you the rules which you should observe in order to maintain the two in their wholesome integrity. Studiously endeavour to control the easily ruffled feelings which so frequently shock the system, mar domestic peace, and, not only so, but positively unhinge and alienate your better feelings if left uncoerced. Maintain, as far as it is humanly possible, a uniform gentility of manner, such a one as you would wish to impress upon the constitution of your child, and which alone can be consistent with a perfect development. Be extremely careful in your interpretation of any imaginary 'slight' or 'inattention,' and, be assured that many of your little troubles will have their basis only on a perverted imagination." (1875: 8-9)

Holland's advice highlights the increased pressures upon the pregnant woman, whose thoughts and actions potentially determine the health of the child, which had been previously in the hands of a divine agency. The anxieties expressed by Holland also reinforce the fact that the mother is seen as potentially sporadic and uncontrollable as well as diseased or disordered; she is in need of medical advice and guidance. Once again, it is apparent that the assertion of medical authority over the body of the mother is a response to the perceived threat of the monstrous maternal body, which points to the permeability of the borders of human and monster.

Creating the Monster

Paradoxically, in trying to construct strict mechanical laws that accounted for

'normal' development, doctors were dependent on the abnormal phenomenon of the monstrous body—a body that they were interested in understanding, and then mastering. The monstrous body began to move into its position as clinical or pathological specimen, and the relationship between the monster and medical authorities became mutually beneficial⁸. Examinations by reputable doctors who could testify to the authenticity of the monstrous condition and "[legitimize] the public's interest in curiosities", helped to boost interest in these living monsters, who were frequently exhibited as part of small touring shows (Bogdan 1988: 26). In addition, "the display of a dead prodigy embalmed as a spectacle, pickled as a specimen, or textualized as an anatomical drawing derived from dissection was equally profitable, and often more readable and manipulable" than its living counterpart (Garland-Thomson 1997: 57). In this sense, monsters could serve to reinforce medical expertise and allow doctors to make profit.

Julia Pastrana (1834-1859), known as the 'Ape Woman', was one such dead prodigy who continued to turn a profit during a display that lasted 100 years after she had died. Following Pastrana's death, five days after giving birth, her husband, Theodore Lent, arranged with Professor Sokolov⁹ of the University of Moscow to have both their bodies embalmed and displayed at the Anatomical Institute for a fee of 500 pounds. However, once Lent heard that Sokolov's embalming handiwork had proved a "minor scientific sensation", he began legal proceedings that eventually allowed him to buy back the bodies and continue to rent them to travelling museums or display them for his profit (Gylseth & Toverid 2001: 69). Matthew Sweet claims, "the pair [mother and son] were exhibited as late as 1973, when the baby was eaten by mice and the body of its mother stolen by vandals while being exhibited at a Fairground in Norway" (2001: 143). Her body is now preserved in the Schreinerske Collections Department Group of Basic Medical Sciences at the Institute of Forensic Medicine in Oslo.

In *Monstrosities: Bodies and British Romanticism* (2003), Paul Younquist relays the details of a similar case. Known as the "Sicilian Dwarf", Caroline Crachami was taken to England in 1824—with her father's permission—by a Dr.

⁸ Dreger illustrates this with regard to intersex in *Hermaphrodites and the Medical Invention of Sex* (1998). According to her, medical expertise was built through an engagement with the hermaphroditic body in the nineteenth century.

⁹ Spelled 'Suckaloff' by Matthew Sweet in *Inventing the Victorians* (2001).

Gilligan, who claimed that the English air would help to cure her cough. As soon as she arrived, however, she was exhibited at his home on Bond Street to the public and to curious physicians who would pay sums of money to handle her to varying degrees. By June of 1824, Crachami was dead, but

death did not put an end to her attractions. In some ways death perfected them, since now the Sicilian Dwarf could be subjected to a medical examination of the most intimate kind. Deprived of his income, Dr. Gilligan made the best of a bad situation by approaching several prominent physicians with the opportunity, for a modest gratuity, to buy Caroline's body. Most refused, but in a deal whose particulars remain a mystery, the Royal College of Surgeons acquired the little cadaver—in the interest, no doubt, of anatomical science. (xii)

To the present day, her 20-inch skeleton is still on display in London at the Hunterian Museum, Royal College of Surgeons. Both examples demonstrate the scientific and commercial value of human monsters. They suggest that 'abnormal' bodies reinforced the power of medicine to control regulatory norms and commodify 'monsters'. Medicine could rationalize the unusual body by acting upon and classifying it, and make a profit by buying, selling, and displaying these specimens; in turn, science "[produced] and [enforced] a cultural norm of human embodiment" (ibid: xi).

Although science sought to 'explain away' the threatening potential of monsters through rational and logical means, the term itself was still employed long into the nineteenth century. Ironically, it became appropriated toward a particular end, namely that of scientific and medical discourse. Conjoined twins, one particular kind of 'monster', were of great interest to medical authorities, who used the term in myriad ways to describe unique anatomical conditions. The minutes from the Obstetrical Society of London in the *British Medical Journal*, recorded by Graily Hewitt, report a Dr. Brunton's reference to "conjoined twin-monsters" and "a double monster" in 1869 (260). In 1875, Holland gave the following reassurance under the headline "Deformed Infants" in his book: "Children are occasionally born deformed and defective, but however extreme the defect may appear, it is of importance to remember that the law regards no monstrosity, born of human parents, unworthy of life, and therefore jealously protects it" (23). In 1881, correspondence from the December 3rd issue of the *British Medical Journal* refers to a rare delivery of conjoined twins: "The first head

that presented, owing to delay in the second stage, was delivered with forceps; this brought the other head forcibly against the abdominal wall above the pubes, and there still being obstruction to delivery, a monster was easily diagnosed" ("Correspondence" 918). Here, medical authorities have assumed a degree of control over the monster because they have labelled it. In Holland's quote, the monster is integrated in a legal discourse that offers protection, which shows that the monster has lost its threatening qualities and is now subject to medical observation and aid. Similarly, in the other two quotations, the term 'monster' operates as a medical category (that allows doctors to assert authority over conjoined twins). Overall, it becomes apparent that the term evolved—from the Middle Ages to the nineteenth century—from a word used to describe wonders or miracles to one used as a means to describe a medical conundrum.

The Freak Show

The examples of Julia Pastrana and Caroline Crachami show that the medical drive to explain and categorize the monstrous body often led to its commodification. The term that is more commonly used when speaking about the commodified monstrous body is that of the 'freak'. There are important historical and conceptual similarities that connect the terms 'monster' and 'freak'. Historically, the rise of the freak show in the nineteenth century, discussed in detail below, partakes in the same desire to exhibit and classify that led medical authorities to turn monstrous bodies into display pieces in museums and anatomical collections. Conceptually, the 'monster' and the 'freak' are similar in that they seek to impose a certain order that clearly distinguishes between the self and other, the human and the monstrous.

Central to recent attempts to think more generally about physical difference is the idea that the meanings attached to bodies are determined by social and cultural context. Thus, the term 'freak' does not describe a pre-existing condition, according to photographer and writer David Hevey, but rather a social construction or act of becoming—a process called 'enfreakment' (1992, 1997). It is "a way of thinking about and presenting people—a frame of mind and a set of practices" that allowed master showmen and their organizations to create specific

situational environments in which other individuals with anomalous bodies were presented as freaks and displayed to entice and captivate a paying audience” (Bogdan 1996: 24). While the process of ‘enfreakment’ fulfilled economic purposes, it also served to assign meaning to the deviant bodies on display. At the same time, the exposure to the freak threatened to unsettle the identities of the spectators themselves.

To understand these complex dynamics, it is necessary to trace the emergence of the freak show and explore its relation to the display of unusual bodies in medical and scientific contexts. Freak Shows saw the rise and fall of their popularity between the mid-nineteenth and mid-twentieth centuries. Robert Bogdan argues that 1841 was particularly significant because P.T. Barnum began exhibiting human curiosities in New York. Within just a few years of taking over the Scudder's American Museum, Barnum's American Museum was thriving because he had transformed it into a major entertainment center that housed a diverse selection of living human oddities. By 1850, the Museum "was the premier attraction of New York City" and freak shows, in general, were flourishing both in the United States and Britain (Bogdan 1996: 33).¹⁰ In “represent[ing] a dramatic resurgence of the tradition of publicly displaying and reading extraordinary bodies”, the freak show provides an important example of the ways in which cultural representation assigns meaning to the raw material of unusual bodies (Garland-Thomson 1997: 58). Historically speaking, it constitutes a paradoxical conceptual space in which the monster evolved into the monster/human—the freak—as we shall see.

One of the main problems that arises when thinking about the process of enfreakment is the materiality of the deviant body to which Hevey’s assessment does not give enough consideration. In his examination of the photographic

¹⁰ For further analysis of the history of the freak show in the United States, see Robert Bogdan’s *Freak Show: Presenting Human Oddities for Amusement and Profit* (1990), Marc Hartzman’s *American Sideshow* (2006), or Rachel Adams’ *Sideshow U.S.A.: Freaks and the American Cultural Imagination* (2001). Rosemarie Garland-Thomson also presents a compelling analysis in chapter 3 of *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* (1997). For an analysis of the British freak show, see *Victorian Freaks: The Social Context of Freakery in Britain* (2008) by Marlene Tromp and *The Spectacle of Deformity: Freak Shows and Modern British Culture* (2009) by Nadja Durbach. In *The Victorian Freak Show: The Significance of Disability and Physical Difference in 19th-Century Fiction* (2009), Lillian Craton discusses the images of physical difference that permeate the fiction of authors such as Dickens and Carroll, and she argues that they offer positive views of bodily difference despite the impetus of the times to prize normality.

representations of disabled people, Hevey does not account for the visual and material bodily difference as a result of which at least some individuals come to be branded as freaks in the first place. The crucial question is whether physical difference should be viewed as the prerequisite to the process of 'enfreakment', or if 'enfreakment' is entirely socially constructed, and thus creates the physical stigmas we perceive and to which we attach meaning. Rather than offer a single answer, it is important to acknowledge that there were different categories of freaks. In his work on freak shows, for instance, Bogdan describes two types of people who were most commonly exhibited as freaks, although he concedes that people often shifted between groups and could fall into both categories simultaneously. The first group comprised individuals who were born with obvious physical abnormalities: conjoined twins, intersexed individuals, dwarfs, and microcephalics, to name just a few. These individuals garnered attention from both spectators and physicians who were interested in Teratology (1988: 6-7). The second group included 'normal'-bodied people of a different cultural or racial background taken out of their own cultural framework. These individuals were placed in stark opposition to a white, western gaze, presented with all of their native cultural paraphernalia (ibid : 6). Writing about British freak shows, Nadja Durbach concludes that "[b]y displaying people of color alongside other 'human oddities,' these types of shows served to reinforce the Victorian construct of white, healthy, middle-class Englishmen as the norm of the perfectly evolved body" (2010: 149). Bogdan makes a similar claim about the American freak show. In both cases, the popularity of this particular brand of freak was driven by the then-current exploration of distant countries, which were viewed as mysterious and exotic. The racially different bodies provided physical evidence of "undiscovered types of humans" that were perceived as lurking far beyond the reaches of the Western world (Bogdan 1988: 6). Their immediate physical marker of difference was racial, but in addition, these individuals also performed their difference.

Saartje Baartman¹¹ or "The Hottentot Venus"¹², for example, was exhibited in London and Paris from 1810 until she died in 1815. According to Garland-

¹¹ Some sources use *Sartje* as the spelling.

Thomson, she was billed a Hottentot, “the exotic label that stood for everything the Englishmen considered himself not to be,” but she was actually a member of the San tribe, brought to London at age 21 as an indentured servant from South Africa (1997: 71). In her study of Baartman, Rachel Holmes describes her as “fantasy made flesh” for the Londoners who flocked to see her in 1810 (2007: 2), and Natasha Gordon-Chipembere describes the “persona of the ‘Hottentot Venus’, infamous for her buttocks and alleged *Hottentot Apron* (extended labia), [as] a creation of the European imagination” (2011: 6; her emphasis). Framed by “a small grass hut and painted boards depicting pastoral African scenery and verdant, exotic plants”, the ‘Hottentot Venus’ was a representation of racial otherness (ibid). She was also the antithesis of accepted notions of femininity. The full description, as summarized by Holmes, is important here:

Venus was simply a synonym for sex; to behold the figure of Venus, or to hear her name, was to be prompted to think about lust, or love. At the same time, the word *Hottentot* signified all that was strange, disturbing, alien, and—possibly—sexually deviant. Some in the audience had heard or read travellers’ tails of mysterious Hottentot women, reputed to have enormous buttocks and strangely elongated labia, and to smoke a great deal. And here she was, [...] tinted gold by the stage light, elevated above [the audience], uniting the full imaginary force of these two powerful myths: Hottentot and Venus. Her skin-tight, skin-coloured body stocking clung to her so snugly that it was plain for all to see that she wore no corset, stockings, or drawers beneath. Most shockingly, the luminous ropes of ivory-coloured ostrich-eggshell beads that cascaded from her neck to her waist failed entirely to conceal her nipples, pert beneath the thin silken fabric. (Holmes 2007: 2)

What becomes apparent in this description is that enfreakment is not simply based on physical difference, but is also, at least partly, a construction or performance. Even in publicity images, Baartman appeared in an array of accessories that included “ostrich feathers, an assortment of pipes, and a bushbuck apron of the design traditionally worn by rural women to cover their genitals for modesty” (ibid: 54). Zachary Macauley, an early campaigner for the abolition of slavery testified to her performance in a letter to the Examiner.

According to his account, which appeared on October 14, 1810: “This poor female is made to walk, to *dance*, to show herself, not for her own advantage, but for the

¹² The “Hottentot Venus” is one of the most popular, widely discussed performers of the nineteenth century. A valuable source on her life (in addition to Holmes) is: *Sara Baartman and the Hottentot Venus: a Ghost Story and a Biography* (2010) by Clifton Crais and Pamela Scully.

profit of her master, who, when she appeared tired, holds up a stick to her, like the wild beast keepers, to intimidate her into obedience" (qtd. in Crais and Scully 2010: 89). Clearly, the "Hottentot Venus" is a constructed performance, brought to Europe to play a role that further reinforced the superior position of the white, western audience.¹³

The constructed nature of enfreakment becomes even more pronounced when considering a third group of freaks, which Bogdan does not discuss. Individuals that were heavily tattooed, for instance, who were not freaks 'by nature', but by choice, had created their own physical difference. Even with freaks belonging to the first group of allegedly 'natural' freaks, the material difference was enhanced, for instance, by elaborate costuming and staging. In all of these cases, enfreakment entails markers of physical difference, which are actively constructed or enhanced to different degrees. Regardless of the group to which these individuals belonged, they were framed as freaks, their differences constructed and presented in such a way to pique the interest of the audience and secure the greatest profit for promoters. In this way, Barnum and his contemporaries capitalized on the public's thirst for entertainment and their curiosity. To what degree the freaks themselves controlled and contributed to their own enfreakment is the question I turn to next.

Freak as Precarious Human

Freaks provided entertainment, and they were a means through which the audience could reaffirm their own normality; they served the audience in myriad ways, as this chapter will discuss. What is left open is the question of the freaks' agency. Sweet argues against too readily accepting that the freak show was merely damaging and exploitative:

[C]ondemning the freak fancier's attitude as patronising or barbaric will simply not suffice; nor will assuming the freak performer to be the pathetic

¹³ *Representation and Black Womanhood: The Legacy of Sarah Baartman* (2011), edited and introduced by Natasha Gordon-Chipembere, is a collection of essays that approaches Baartman not through "an archived, colonial lens" that "confine[s] her to the space of victim, prostitute, and drunkard [...]", but as Sarah Baartman, the dynamic and improperly labelled woman behind the narrative and visual caricatures (4). The collection traces Baartman's trajectory from "nineteenth-century narrative to contemporary manifestations of a dominant Euro-American gaze on African and Diasporic women's bodies" (5).

victim of exploitation. The culture of the nineteenth-century exhibition circuit was too complex and ambiguous to allow for such a reductive reading of the relationship between freaks and their fans. (2001: 153)

Niall Richardson draws a similar conclusion, pointing to the possibility that freak show audiences were more aware of conventions of representation than common opinion may acknowledge. To view the audience as 'unaware' "may be a very reductive (and indeed elitist) view of freak show spectators as perhaps these spectators *did* acknowledge the constructed or fabricated nature of the 'freak' but still enjoyed it nonetheless" (2010: 7; his emphasis). The relationship between viewer and exhibit was at the very least symbiotic, but could perhaps even be considered mutually beneficial. The freak show did, after all, offer the people on display a recognizable and valid subject position, even if it was precarious and ambivalent. At the very moment that freaks are hailed into their positions as freaks they also assume a subject position that bestows upon them a certain degree of recognition, validity and agency. On a very practical level, this was reflected economically, as working in a freak show allowed individuals to earn money and live an independent existence. According to Sweet, "their rates of pay compared favourably with those of others in the entertainment industry. In the United States in the late nineteenth century, stage actors received about thirty-five to eighty dollars a week. The top performers on the Dime Museum circuit might take home five hundred dollars per week" (2001: 147).

Another potentially empowering aspect of the freak show was the emergence of a collective freak identity, the idea of being one of many, rather than just an isolated individual. Within their community, freaks could gain a sense of themselves as 'part of', instead of 'apart from', the larger group. As Bogdan asserts, by mid-century, freak shows were a means by which human curiosities became part of a collective that "was in the process of developing a way of life apart from the mainstream" (1988: 30). He marks the absorption of freaks into a social collective as a significant change and points to the fact that prior to this, "human curiosities floated precariously, without roots" (ibid). The community that emerged as a result of the freak show could serve potentially as a space in which freaks could exercise collective agency. Linked by their understanding of each other's struggles and common circumstances, freaks could—as many other

collective groups have done to political and social ends—emerge as a tool for change. Furthermore, a collective identity could encourage freaks to perceive the power dynamic between themselves and their audience as reversed. The sense of ‘we’ and ‘us’ would legitimize their perception that they were the more powerful party in the social choreography between freak and spectator. After all, people were coming to freak shows and spending their money to see them.

Garland-Thomson, however, points to the destructive force of this collective identity. For her, the freak show was particularly damaging because it "[eradicat]ed distinctions among a wide variety of bodies, conflating them under the single sign of the freak-as-other" (1997: 62). For her, the collective freak identity was "the consequence of a comparative relationship in which those who control the social discourse and the means of representation recruit the seeming truth of the body to claim the center for themselves" (ibid: 62-3).¹⁴ Coleman agrees, classifying this type of community as insular—a community built around and maintained by difference. Rather than empowering the stigmatized, it strips them of their power and at the same time gives them a sense of false superiority in that they are pushed to the margins of ‘regular’ society rather than permitted to live within it (1997: 223). While they do operate and thrive within a community, it is still a ‘forced’ community, formed because the people within it are prevented from existing freely within any other. In this sense, freak show culture, which existed in the private space behind the stage, can be seen as emblematic of the trend to push extraordinary bodies to the margins and to further stabilize the norm. The freak collectives thrived because they did not lay claim to cultural ‘normalcy’; quite the contrary, their exclusion from the realm of the ‘normal’ helped to constitute and maintain the latter in the first place.

The argument over whether freak shows were empowering or disempowering does not detract from the general consensus that the word ‘freak’ assumes a degree of humanity that had not been attached to the term ‘monster’.

¹⁴Interestingly, the freak collective reflected similar power structures and exclusionary dynamics to those found in society at large. While we can certainly argue that the collective mainstream identity from which freaks were excluded did its part to disempower freaks in general, we can also say that those social collectives formed by freaks mirrored those of mainstream culture. Even though the freak society was the result of a process of exclusion, it comprised similar exclusionary hierarchies. Certain freaks, such as conjoined twins, were prized over others, for example, and there was often segregation between performers and showmen or managers.

After all, stigma is a *human* difference, albeit one that connotes a relationship of superiority. Garland-Thomson disagrees with the idea that the freak was granted humanity, arguing that “the cardinal principle of enfreakment [is] that the body envelops and obliterates the freak’s potential humanity. When the body becomes pure text, a freak has been produced from a physically disabled human being” (1997: 59). While it is easy to agree with her from a modern perspective in which the obvious exposition of unusual bodies is often viewed as tasteless and demeaning, it is important to highlight the positive effects of the freak show in its historical context, where it was at least a ‘first step’ toward validating human bodily difference. Freak shows forced the public to see not just an anomalous body on display, but something that was perhaps a little closer to human than they could have imagined: the human was recognizable in the freak.

Despite the human potential of the freak, the paradoxical dynamics that Margrit Shildrick analyzes with regard to the monster are maintained. She describes the monster as

the other who must be excluded in order to secure the boundaries of the same, the other who is recognizable by the lack of resemblance. Nonetheless, what makes monsters really interesting from my own perspective as a feminist postmodernist, is [...] that monsters are also the spectre of the same. We may call them, then, the other(side). The point is that monsters can signify both the binary opposition between the natural and non-natural, where the primary term confers value, and at the same time, the trace within that signals disruption. In other words, they speak to both radical otherness and to the always already other at the heart of identity. [...] The issue is not so much that monsters threaten to overrun the boundaries of the proper, as that they promise to dissolve them. (1996: 2)

In the freak show, the source of excitement and anxiety for spectators was hypothesizing that freaks were—at least in part—the same as them. At the same time that the recognition of ‘self in other’ gave spectators a vicarious thrill, it also triggered a compassionate response, which both maintained and destabilized the self/other binary. In *Woeful Afflictions: Disability and Sentimentality in Victorian America* (1999), Mary Klages argues that representations of disabled people since the late eighteenth century have been sentimental, helping to construct the generalist view that disabled people are “dependent sufferers,” “silent spectacles,” “permanent children”, and “feminized in their dependence on others’ compassion”

(2). The importance of disabled bodies, according to her, “has been in their ability [...] to produce a sympathetic or sentimental response in non-disabled people” (ibid). Additionally, Lauren Berlant’s introduction to *Compassion: The Culture and Politics of an Emotion* (2004) is useful to this discussion. According to Berlant, compassion “implies a social relation between spectators and sufferers” (1); the word “carries the weight of ongoing debates about the ethics of privilege” (ibid). People who identify with the privileged ‘norm’ of society feel compelled to show compassion because of an innate, social need to be part of a collective, not of spectators, but “ameliorative actor[s]” (ibid). Yet as Berlant notes, “the Freudian notion of *Schadenfreude*, the pleasure one takes in the pain of another, only begins to tell the unfinished story of the modern incitement to feel compassionately—even while being entertained” (ibid: 5.). This explanation of compassion applies to the freak show, which in addition to promoting the recognition of ‘self *in* other’, also clearly defined spectators and spectacles as ‘self *and* other’. While spectators may have felt compassion for those on display—perhaps even because they wanted to assuage the guilt that resulted from looking, from participating as spectators—they also felt the corresponding pleasure of being entertained. The freak show actually relied on a blend of entertainment and sentimentality; the show merged the two to produce the freak.

This conflation of entertainment and sentimentality is central to the pamphlets and other publicity materials that were used to market freaks. Garland-Thomson discusses extensively the sentimental representations of disability in nineteenth-century fiction, but she overlooks that same type of representation—played out in penny pamphlets and photographs—in the freak shows themselves. Elaborate stories concocted in lectures and biographical pamphlets that were often available for sale, especially at the height of the freak show’s popularity, provided the audience with the ‘true-life’ account of the freak. Some were presented as having special skills and talents, or a long list of impressive accomplishments. Biographical information, including family stories, childhood memories, and personal difficulties, in addition to a list of the places where they had been exhibited, testimonials from doctors and scientific experts who had examined them and could vouch for the authenticity of their condition, and endorsements from authority figures were all included to bolster their legitimacy

and appeal. At the same time, these ‘facts’, which provided human curiosities with a recognizable and relatable identity, brought them closer to the realm of the human. For example, Joseph Merrick, more commonly known as the ‘Elephant Man’, included the following information in his pamphlet titled “The Autobiography of Joseph Carey Merrick”:

I first saw the light on the 5th of August, 1860, I was born in Lee Street, Wharf Street, Leicester. The deformity which I am now exhibiting was caused by my mother being frightened by an Elephant; my mother was going along the street when a procession of Animals were passing by, there was a terrible crush of people to see them, and unfortunately she was pushed under the Elephant’s feet, which frightened her very much; this occurring during a time of pregnancy was the cause of my deformity.

The measurement round my head is 36 inches, there is a large substance of flesh as the back as large as a breakfast cup, the other part in a manner of speaking is like hills and valleys, all lumped together, while the face is such a sight that no one could describe it. The right hand is almost the size and shape of an Elephant’s foreleg, measuring 12 inches round the wrist and 5 inches round one of the fingers; the other hand and arm is no larger than that of a girl ten years of age, although it is well proportioned. My feet and legs are covered with thick lumpy skin, also my body, like that of an Elephant, and almost the same colour, in fact, no one would believe until they saw it, that such a thing could exist. It was not perceived much at birth, but began to develop itself when at the age of 5 years.

I went to school like other children until I was about 11 or 12 years of age, when the greatest misfortune of my life occurred, namely—the death of my mother, peace to her, she was a good mother to me; after she died my father broke up his home and went to lodgings; unfortunately for me he married his landlady; henceforth I never had one moment’s comfort, she having children of her own, and I not being so handsome as they, together with my deformity, she was the means of making my life a perfect misery; lame and deformed as I was, I ran, or rather walked away from home two or three times, but suppose father had some spark of parental feeling left, so he induced me to return home again. The best friend I had in those days was my father’s brother, Mr Merrick, Hair Dresser, Church Gate, Leicester.

[...] I was sent about the town to see if I could procure work, but being lame and deformed no one would employ me; when I went home for my meals, my step-mother used to say I had not been to seek for work. I was taunted and sneered at so that I would not go home to my meals, and used to stay in the streets with an hungry belly rather than return for anything to eat, what few half-meals I did have, I was taunted with the remark—‘That’s more than you have earned.’

Being unable to get employment my father got me a pedlar’s license to hawk the town, but being deformed, people would not come to the door to buy my wares. In consequence of my ill luck my life was again made a misery to me, so that I again ran away and went hawking on my own account, but my deformity had grown to such an extent, so that I could not

move around the town without having a crowd of people gather around me. I then went into the infirmary at Leicester, where I remained for two or three years, when I had to undergo an operation on my face, having three or four ounces of flesh cut away; so thought I, I'll get my living by being exhibited around the country. Knowing Mr Sam Torr, Gladstone Vaults, Wharf Street, Leicester, went in for Novelties, I wrote to him, he came to see me, and soon arranged matters, recommending me to Mr Ellis, Bee-hive Inn, Nottingham, from whom I received the greatest kindness and attention. (Merrick 2010: Appendix 1)

Merrick's repeated mention of his deformity together with the vivid description of its impact on his life is entertaining and sentimental. It serves to present a gripping story while also evoking the reader's compassion. That freaks were embedded in such narratives—even if those narratives were embellished or completely fabricated—suggests that there was more to them than the raw material bodies the spectators perceived on stage. In this way, physical difference could be embedded within a recognizably human story, allowing for identification with the freak. Thus, the difference between self and other and human and freak could be diminished. In fact, for Fiedler, it is one of the key characteristics of the freak—as opposed to the monster—that the freak "is one of us, the human child of human parents, however altered by forces we do not quite understand into something mythic and mysterious" (1978: 24). A written account of a freak's life, or even a photograph, permitted greater accessibility to him or her; spectators could potentially connect aspects of their own lives to the lives of the people on display. This negotiation of sameness and difference, resulting from the reading of these accounts, was certainly encouraged by the fact that freaks like Merrick were at times writing their own stories. The freak show made the freak someone that the 'Normate', "the constructed identity of those who, by way of the bodily configurations and cultural capital they assume, can step into the position of authority and wield the power it grants them", could relate to (Garland-Thomson 1997: 8).

However, it would be reductive to assume that these narratives always necessarily challenged the binaries between spectator and freak. For a start, there is little evidence to suggest who actually read these pamphlets, and it is difficult to trace how these stories actually impacted the reader's feelings towards the freaks described. Moreover, the reader's position of authority and sense of 'normalcy'

could also be strengthened through these texts. After all, autobiographical narratives like Merrick's not only allowed the freak to speak directly to their audience in order to appeal to their compassion, but also, paradoxically, to present themselves as 'other' by highlighting their physical differences. Merrick's repeated description of himself as deformed and sick potentially places him in a subordinate position against which the reader can define his or her own sense of 'normalcy'. Again, there existed the potential to feel simultaneously close to *and* distant from the freak, who is not quite same, but not quite 'other' either.

Not Quite Same; Not Quite 'Other'

Despite the traces of humanity produced through sentimental representations of physical difference, the freak was not removed completely from the realm of the 'other'. The freak does not neatly blend into any category at all and is thus positioned-in a precarious space between the possible and the impossible. Instead,

the true Freak challenges the conventional boundaries between male and female, sexed and sexless, animal and human, large and small, self and other, and consequently reality and illusion, experience and fantasy, fact and myth. (Fiedler 1978: 24)

In this sense, it is important to highlight the paradoxical nature of the freak, which simultaneously reinforces and tears down the border between 'them' and 'us', subject and object, empowered and disenfranchised, power and disempowerment.

This is perhaps most apparent when focusing on the complex spectator-freak dynamic. Because the freak was always precariously at the human border or near the border of human, it was both appealing and appalling to curious spectators. In *Staring: How We Look* (2009), Garland-Thomson investigates the paradoxical nature of curiosity, which "names both the desire to render the strange familiar and the strange thing itself. The force of curiosity makes something into a curiosity" (64). On the one hand, curiosity is a positive force—the catalyst that "make[s] the unknown intelligible, [and] incorporate[s] the unusual into our understandings of the usual" (ibid: 48). On the other hand, however, curiosity "gobbles up the object of its contemplation. Curiosity recontextualizes its object. Curiosity in the service of mastery tames the extraordinary" (ibid: 64).

This paradox is manifested in the spectator's relationship with the freak. Even though the spectator was deemed superior by means of his or her alleged 'normality', encountering a freak destabilized the spectator's identity and pointed at his or her lack of control. The reason for this is that the spectator's allegedly superior subject position is fundamentally dependent on constructing the freak as other—making the freak a curiosity. Thus the subject/object status of the freak and spectator are interconnected and interdependent; the freak is "both the alien other who threatens the corporeal and psychic boundaries of the embodied self [and] an intrinsic, but unstable, part of the [spectator's] self" (Shildrick & Price 1999: 7). The freak show, in its power to be both subversive and conservative, empowering and disempowering (for both spectator and freak), is a space constructed by normative cultural structures, but also a space where these power structures can be renegotiated. In this sense, it is difficult to determine whether freak shows were "a socially constructed phenomenon of commercial entertainment and a product of unequal social relations, oppression, and exploitation" (Gerber 1996: 38) or a "refuge in a world where there were others similarly situated" (Bogdan 1996: 35).

As a result of these complex power structures, the position of the freak is volatile: the freak is objectified but simultaneously granted a precarious subject status. Some writers have challenged the very validity of the 'freak' as a category of identity, arguing that the role of the freak is nothing but a performance. For Bogdan (1988), the freak "can teach us not to confuse the role a person plays with who that person actually is" (10). His conclusion is somewhat problematic in that personal identity is largely based on or constructed from others' recognition and cognizance of the individual. In asserting a subjectivity that lies behind the role of the freak, Bogdan underestimates the paradoxical quality of the 'freak' label that bestows subjectivity on the freak, but also undermines and negates it at the same time.

The power of the staring spectator is crucial, as it effectively constructs the freak as "the other who must be excluded in order to secure the boundaries of the same, the other who is recognizable by the lack of resemblance" (Shildrick 1996: 2). Through the spectator's eyes, the freak becomes a spectacle and an object. As such, the freak

simultaneously testifie[s] to the physical and ideological normalcy of the spectator and witnesse[s] the implicit agreement assigning a coercive deviance to [him/herself]. This determining relation between observer and observed was mutually defining and yet unreciprocal, as it imposed on the freak the silence, anonymity, and passivity characteristic of objectification. (Garland-Thomson 1997: 62)

In her article, "Ways of Staring" (2006), Garland-Thomson further elaborates on the power dynamics associated with the stare, which she sets apart from the gaze:

We may gaze at what we desire, but we stare at what astonishes us. Because staring both registers and demands a response, it enacts a drama about the people involved. This vivid form of human communication reveals who we imagine ourselves and others to be. [...] Interactive and fluid, the stare is always powerful and awakening. A kind of potent social choreography, staring marks the body of the staree and enacts a dynamic visual exchange between a spectator and spectacle. (174, 175)

The act of marking to which Garland-Thomson refers assigns meaning to the body of the spectacle, classifying it as the inferior partner in the relationship: the object of the stare. Thus the subject/spectator asserted him/herself by objectifying the freak. It is the disembodied, indistinguishable audience that was further normalized as part of this "institutionalized social process of enfreakment" (Garland-Thomson 1996: 10). In other words, in becoming a collective of 'normals' who mark the 'other' body through visual cognition, the audience affirms its position as superior in the exchange. Staring at someone who does not conform to our predictable view of the world is our attempt to make sense of that which has disrupted our sense of the familiar. Staring, according to Garland-Thomson, is a way of solving a cognitive problem.

On a historical level, one reason the freak show became so popular in the nineteenth century is that it constructed the extraordinary body in a way that served to counter the numerous disturbances associated with the then-current drive toward industrialization, urbanization, and colonization by granting a sense of 'normalcy' to the spectator. Moreover, the freak show assured the spectator of his or her role as part of a social collective represented in the audience and set apart from the freaks on stage. Relevant to this idea of a 'normal' social collective, which is distinguishable from the unfamiliar form, is Lennard Davis' observation that "the coming into consciousness in English of an idea of 'the norm' [takes place] from 1840-1860" (1997: 10). It was an idea that was born from the 'ideal',

a word we find dating from the seventeenth century. Without making too simplistic a division in the historical chronotope, one can nevertheless try to imagine a world in which the hegemony of normalcy does not exist. Rather, what we have is the ideal body, as exemplified in the tradition of nude Venuses, for example. This divine body, then, this ideal body, is not attainable by the human. There is in such societies no demand that populations have bodies that conform to the ideal. By contrast, the *grotesque* as a visual form was inversely related to the concept of the ideal and its corollary that all bodies are in some sense disabled. In that mode, the grotesque is a signifier of the people, of common life. The grotesque permeated culture and signified common humanity. (ibid: 10-11)

The 'ideal' was not used to describe the human prior to the mid-nineteenth century, when it was a concept manifested only in divine bodies, which human beings could never obtain. Instead, as human bodies, they were all disabled, or grotesque; the grotesque constituted the 'norm'. That concept of the 'norm' evolved into a more common, modern usage in part because of the field of statistics, which shifted from a way of compiling information about the State into a means to describe the common man or woman. Davis attributes the cause of the genesis of statistics to two people: the first was Bisset Hawkins, who in 1829 formulated medical statistics; the second was French statistician, Adolphe Quetelet (1796-1847), "who contributed the most to a generalized notion of the normal as imperative" (ibid: 11) and developed a "scientific justification for moderation and middle-class ideology" by formulating a concept of the average man that was based on physical characteristics and measured variables (ibid). As a result of his work, the average became inextricably linked to the ideal. But while the ideal did not demand or even expect imitation, "the concept of a norm [...] implies that the majority of the population must or should somehow be part of the norm" (ibid: 13). Uniqueness "came to be read as deviance, while the common became the basis of normalcy" (Garland-Thomson 1997: 67). Those who did not fall under the umbrella of the statistically average were seen as anomalous. This is crucial with regard to the freak show: the body on display was, because of its visual difference, a material reminder of the reassuring fact that the spectator was part of the collective 'norm'.

While the body on display could reinforce the audience's construction of normality and their place within that construction, it was also appealing to an audience who perhaps saw their own lives as mundane and their own bodies as

strangely ordinary or average. The extraordinary body was exotic and defiantly 'other', "[symbolizing] a potential for individual freedom denied by cultural pressures toward standardization" (Garland-Thomson 1997: 68). As such, spectators were simultaneously drawn to and repulsed by it: the "perverse pleasure of voyeurism and identification is counterbalanced by horror at the blurring of identities (sexual, corporeal, personal) that witness our chaotic and insecure identities" (Grosz 1996: 64). Once again, the complex dynamics of the freak show simultaneously affirm and subvert the binaries of freak and spectator, subject and object, sameness and difference.

Conjoined Twins as Self and 'Other'

As has been mentioned above, conjoined twins were part of the medical discourse on monstrosity as well as the emerging freak show culture of the nineteenth century. As medical specimens and freaks, they were displayed publically and partook in the processes of commodification and objectification outlined above. Like other freaks, the spectator's encounter with conjoined twins helped to define the spectators as part of a collective norm from which conjoined twins were excluded. However, because conjoined twins challenge the very borders of the self and the notion of the subject, as has been discussed in the introduction, the encounter also unsettled the spectators' idea of the self as one person, one body, and disturbed the borders between self and other in particularly pertinent ways. For although conjoined twins may more readily look like 'us' in terms of their appearance, they simultaneously challenge fundamental ideas of what it means to be a human subject. Conjoined twins "traverse the very boundaries that secure the 'normal' subject in its given identity and sexuality" (Grosz 1996: 64) and "[provoke] a variety of emotional responses, from wonder to confusion, curiosity to pity, amusement to awe, and most of all, an intense desire to contain and interpret" (Pingree 1996: 173).

Millie-Christine McKoy (1851-1912) the 'two-headed Nightingale', for instance, upset notions of the self as a single, autonomous body. Paradoxically, Millie and Christine recognized themselves as two distinct people, but preferred to be referred to as one:

Although we speak of ourselves in the plural we feel as but *one person*; in fact as such we have ever been regarded, although we bear the names Millie and Christina. One thing is certain, we would not wish to be severed, even if science could effect a separation. We are contented with our lot, and are happy as the day is long. We have but *one heart*, one feeling in common, one desire, one purpose. (McKoy 1885: 20)¹⁵

This use of language originated with their family, who always referred to them in the singular. While according to Joanne Martell in *Millie-Christine: Fearfully and Wonderfully Made* (2000), "[s]trangers saw them as twins, [...] to [their mother], Millie-Christine was her baby, her child. Singular. The family called her 'Sister'" (5). In celebrating their 'oneness' and in claiming to be content with their shared body while also defining themselves as separate individuals, the girls unsettled understandings of physical 'normalcy' and renegotiated the relation between body and self, thereby contributing even further to the contradictory reaction of the spectator to their conjoinment.

As children that had been born into slavery in the American south, these pyopagus¹⁶ twin girls were voiceless and could do nothing to prevent their exhibition. Stolen at a young age by a rival showmen of their owner, Millie and Christine were frequently exhibited by their captors, in privacy and for a fee, to local members of the medical community who were interested in the twins' unique bodily formation; it therefore became commonplace for the girls to be subjected to full physical examinations. That they had "separate bladders, but one common vagina, one uterus to be recognized, and one perfect anus" was a common fact used as a means of building interest in the girls (qtd. in Dreger 2004: 121). This information, included in their penny pamphlets, contributed to the mystery of their condition at the very same time it provoked interest from and titillated spectators who wanted to know how they functioned sexually. Because this information came from medical professionals, it was not considered pornographic, but rather "safe and acceptable. [...] In this way, doctors could gentrify and legitimate a performance that might otherwise be simply distasteful. Medical discourse was deliberately used to ward off charges of pornography, even while it was used to titillate" (Dreger 2004: 122-3). In her discussion of the twins,

¹⁵ This excerpt is from the pamphlet, "Biographical Sketch of Millie-Christine" (1885), which can be found in Human Freaks Box 2, John Johnson Collection, Oxford University.

¹⁶ Pyopagus refers to conjoined twins joined at the sacrum.

Durbach analyzes the girls' souvenir pamphlet "Biographical Sketch of Millie-Christine", which suggests that they were sexually attractive to both public and professional audiences:

It [the pamphlet] linked her [Millie-Christine] to the prostitute by underscoring that one had to pay to visit her, but at the same time it firmly situated her within the economic and domestic accounting of the middle-class marriage market. The sexuality of 'the maid with the duplex cranium' was also enhanced by the exhibition of her bare flesh, for the public was allowed to see the place where their bodies joined. While their pamphlet assured that this part of their back could be glimpsed 'without any infringement of modesty,' the medical professional was allowed more access not just to the exterior, but to the deepest recesses of their bodies. Bland Sutton, who may or may not have personally examined the twins, maintained that 'the anal orifice was single' and that while 'the vulva appeared to be single,' within it were 'two vaginal and two urethral orifices. (2010: 83)

While the girls were trained in music, languages, etiquette, and social graces, their unique anatomy drew interest because it directly and fully attacked the idea of bodily borders on two levels: they were physically one, and they were sexually one. Interestingly, the Tocci Brothers, Giacomo and Giovanni, had the same type of condition as Millie-Christine (two separate bodies from the waist up, but only one from the waist down), but they seemed not to have endured the intense physical examinations to which the girls were frequently subjected.

In a similar case, Lalloo, "the double-bodied Hindoo Boy", who began exhibiting himself in the U.K. in 1887, attracted attention because he billed himself as both conjoined twin and hermaphrodite. Attached to his chest was a parasitic twin, Lala, who was—according to his marketing materials—female. This unique formation, according to Durbach,

raised concerns about the sexual potential of a double-sexed body. Although they never explicitly addressed the sexual relationship between Lalloo and Lala, the promotional materials that accompanied the exhibition and the medical case reports that circulated in professional journals suggested that his body was intriguing because of the ways in which it exploited late Victorian anxieties about masturbation, incest, pedophilia, and child marriage. (2010: 58-9)

There is no doubt that his male body, permanently united with a female, garnered attention because it raised questions about the distinction between the male and female body, a topic that was also debated intensely, for instance, in sexological

discourses of the time. In addition, Lalloo's body was particularly unsettling to the viewer because it was at once singular and dual. Lala, the non-functioning parasitic body that protruded from just above his groin, was the locus of anxiety about sexual deviance, and the fact that showmen changed the sex of the parasitic twin from male to female at some point during Lalloo's career is indicative of the appeal of this type of deviance.

This type of blurring of boundaries, which alludes to a kind of sexual freedom and mingling of bodies, fed into social anxieties, but also held out the promise of transgression. The body of the conjoined twin, therefore, provided a site onto which spectators could project their fantasies. As Fiedler explains, "In all ages, joined twins have evoked erotic fantasies in their audiences, since they suggest inevitably the possibility of multiple fornication—or at least the impossibility of sexual privacy" (1978: 206). This was especially true of Daisy and Violet Hilton (1908-1969)¹⁷, the vaudeville stars of the 1920's, who "proved more titillating than most, since they were attractive even as little girls, with bottle curls and bows in their hair, and all the more so when they continued in that guise of innocence long after puberty" (ibid).¹⁸ As part of the publicity surrounding the release of Tod Browning's *Freaks* (1932), a film about sideshow performers, in which they starred, posters were distributed with "Do Siamese Twins Make Love?" printed alongside several other questions the movie claimed to address. This again points to the fascination that spectators had with the sexualized body of conjoined twins—*female* conjoined twins in particular.

In addition to the threat that conjoined twins posed to notions of bodily and sexual borders, they also illuminated the tension between wanting to fit comfortably within a larger collective and desiring to be an individual. They were, therefore, emblematic of the anxiety that plagued American culture in the heyday of the freak show, an example of the extraordinary body that "symbolized a potential for individual freedom denied by cultural pressures toward sameness" (Garland-Thomson 1997: 68). Conjoined twins were, in a sense, a "national

¹⁷ For a comparative study of Millie-Christine McKoy and Daisy and Violet Hilton, see *Conjoined Twins in Black and White: The Lives of Millie-Christine McKoy and Daisy and Violet Hilton* (2009) by Linda Frost.

¹⁸ See Dean Jensen's *The Lives and Loves of Daisy and Violet Hilton: A True Story of Conjoined Twins* (2006) for further discussion.

fantasy and a national nightmare. That is, the prospect of merged selves corporealized in conjoined twins both reflects a democratic imperative—where all selves are in a sense the same, interchangeable self—and imperils the stability of unique selfhood" (Pingree 1996: 174). Generally then, conjoined twins embody the tension between individuality and collective identity, a tension that exists in all debates concerning identity, and they point to a reconciliation of the two. Their unique anatomy lends itself to perspectives that merge two seemingly oppositional positions.

In addition, conjoined twins served to challenge stereotypical gender and sexual norms. According to Pingree, Daisy and Violet were a particular menace to the accepted standard of life because they were attractive, successful and happy as they were: single (as in not married) and doubly female. In other words, they threatened what was generally seen as the only valid way of life for a female: to get married, have children and remain tied to the home. The twins'

particular form of aberration perfectly embodies what many by then had come to fear: that a woman's body might not be able to be controlled; that heterosexual, companionate marriage might not be the only form of intimate 'bonding' between two people; and that the division between public and private might not be so clear after all. (Pingree 1996: 183)

Bogdan asserts that, "although marriage was a theme in the presentation of Chang and Eng Bunker, their marriage itself was not a public event" (1988: 204) while, for the Hilton sisters,

marriage was a constant issue in full public view. Indeed, it encouraged much of the publicity they received, for it titillated the general public. Being normal meant establishing nuptial ties, yet the intimacies of marriage were allowed only under the most private circumstances—to which, of course, conjoined twins had no access. (ibid: 201)

The body of the conjoined twin compromised the division between self and other; there was no border between public and private space, one body and another. Chang and Eng were permitted to marry (although it did cause some controversy), but the case was different for Daisy and Violet, who had to fight for the right to marry. In 1934, Violet and Maurice Lambert's petition to marry was turned down in 21 different states "for essentially similar reasons: 'on moral grounds'; 'on ground that bride is a Siamese twin'; on 'the question of morality and decency'; 'as a matter of public policy'" (Pingree 1996: 181). Moreover, Daisy's eventual

marriage failed with the bridegroom claiming: "'I guess I just am not the type of fellow that should marry a Siamese twin.... As far as being a bridegroom under such conditions is concerned, I suppose I am what you might call a hermit'" (qtd. in Drimmer 1991: 54). Daisy and Violet posed a threat, not just to the idea of marriage, but also to heterosexuality in general, because they were two women in an intimate relationship that closely resembled a marriage. It would logically follow then, that the twins' configuration was dangerous to the heterosexual male's identity as the most powerful element of the prevailing social norm. In fact, it was

precisely their attachment to each other, rather than to a man, that [...] made their image more haunting to a conservative male audience than other female 'freaks' who also might have been earning lots of money. That is, [their] conjunction [...], one that literally and symbolically approximated the marriage bond, was precisely what made them so profitable and dangerous. (Pingree 1996: 177)

Again, Daisy and Violet were simultaneously appealing and appalling because of their potential sexual autonomy. This theme of sexuality and conjoinment is a common thread in the chapters that follow, but it is one that will be addressed explicitly in chapter five.

The Space of the Freak Show

As has been shown, the encounter with conjoined twins is often associated with the idea of danger, because it has the ability to make the spectator uncomfortably aware of the unstable aspects of one's own self. However, by displaying human oddities in elaborate, carefully contrived spaces that created both a literal and metaphorical distance between spectators and those on display, freak shows offered spectators both safety and excitement. The freak was set apart on a platform that "both mapped the boundaries of human physical and cultural otherness and generated a liminal space where ontological categories mingled" (Garland-Thomson 1997: 69). Spectators stared at and examined the deviant 'other' from an illusory safe physical distance, thereby maintaining their identification with a 'normal' cultural collective.

For Daisy and Violet, whose fame peaked during the mid-twentieth century, the stage was crucial. The only difference was that rather than appear in a typical freak show, the twins were part of the entertainment and celebrity culture, a culture that also managed to confuse the private and public space. Their appearance in *Freaks* was not only a re-enactment of the freak show, but also a means for the cinema audience to view the freak at an even greater and thus safe distance, but also closer than ever before due to the (at the time comparatively new) cinematographic technique of the close-up. In either case, the arrangement of separation, according to Garland-Thomson,

ritualized the relationship between self and cultural other. As in the social relations of domination and subordination based on race and gender, here, too, the differentiating stigmata literally took center stage, magnified and intensified, while the unmarked position of power, agency, and voice remained veiled. (1997: 62)

The physical, spatial distance between observer and observed served to reinforce the idea of the norm, "[confirming] the viewer as bounded, belonging to a 'proper' social category" while the exhibits were distinctly separate and with their own kind (Grosz 1996: 65).

From Freak to Patient

Toward the mid-twentieth century, freak shows saw a rapid decline in popularity for a number of reasons. According to Bogdan, "[b]y 1940, economic hard times, technological and geographical changes, competition from other forms of entertainment, the medicalization of human differences, and changed public taste resulted in a serious decline in the number and popularity of freak shows" (1996: 23). To this list of reasons, David Gerber adds, "the growth of ideologies and social movements concerned with minority rights [and] the explicitly moral rejection of the freak show" (1996: 45). As the previous discussion has shown, the medicalization of monstrous bodies in the nineteenth century tended to commodify and display physical differences in much the same way as the freak show. However, over the course of the twentieth century, medicalization together with shifting ethical concerns influenced changes in the public perception and cultural construction of those with physical anomalies. In contrast to the freak,

who challenged the borders of the possible and the impossible, patients were clearly within the realm of possibility, othered because they were victims of an identifiable, clinical sickness or disability.

In contrast to the spectator, whose stare affirms its own normativity, the medical gaze views the unusual body as a diagnosable phenomenon:

[T]he living body becomes, in the process of clinical anatomy, a living text, that is to say, material to be read and interpreted by a medical gaze that can pick up all its diseases and functions. Anatomy results in a representation of the body as being clear and distinct—*visible* and therefore intelligible.” (Braidotti 1994: 22; her emphasis)

Once it was understood as visible and intelligible, the body also emerged as fixable. It was therefore up to medical professionals to restore control, shape and familiarity to otherwise chaotic bodies. Consequently, the unusual bodies displayed in freak shows were moved from the public sphere into the medical one and "the wondrous monsters of antiquity, which became the fascinating freaks of the nineteenth century, transformed into the disabled people of the later twentieth century" (Garland-Thomson 1997: 58). As the following chapter will demonstrate, the emphasis on difference as diagnosable phenomenon is a condition of the medical model of disability, which is upheld in documentaries that re-present separation surgeries of conjoined twins.

Chapter 2:

Televised Medicine & the Surgical Construction of Conjoined Twins

The previous chapter began to trace the development from freak to patient. Even after this shift, certain dynamics of the freak show persisted in medical discourse and practice, as well as their representations in popular culture. This is the conceptual space of the freak show, which transcends a specific historical moment and feeds into contemporary discourses and representations of the disabled body. This chapter focuses on medical documentaries about conjoined twins to show how a medical model of disability that sets out to treat patients rather than display freaks nevertheless maintains key dynamics of the freak show: the unusual body is still defined by the professional, who in this case is the doctor or medical specialist, and the disabled person, as the “object of visual difference”, continues to be displayed and objectified (Garland-Thomson 1997: 18). Through their focus on surgical alterations of the unusual body, the medical documentaries discussed in this chapter inscribe ideals of ‘normalcy’ that continue to portray conjoined twins as objects in need of medical care. Thus, medical documentaries raise questions concerning the body, agency, and subjectivity, which have been introduced in the previous chapter and connect the nineteenth-century freak show to the late twentieth- and twenty-first century genre of the medical documentary.

The Medical Construction of the Body

Following Foucault, medical discourse provides one example of bio-power, the complex strategies through which individual subjects and entire populations are governed and regulated. Constructing the ideal of the ‘healthy’ body, which is often white, male, heterosexual and able-bodied, medicine produces and affirms certain norms, which are then projected onto the body and internalized by the subject. Foucault comments on these plastic and manipulable bodies in *Discipline and Punishment* (1977), where he describes the ‘docile body’, a body that “may be subjected, used, transformed and improved” (136). The docile body is both “useful” and “intelligible”; it is regulated so as to support discursive notions of

what is 'healthy' and 'normal' and thus does not offend or disturb an understanding of the body based on social norms (ibid).

At the same time, medical discourse creates 'other' bodies, which are pathologized and marked as deviant or disabled. According to Shelley Tremain, in *Foucault and the Government of Disability* (2005), Foucault's concept of bio-power is crucial to disability studies because bio-power is a system of objectification:

For during the past two centuries, in particular, a vast apparatus, erected to secure the well-being of the general population, has caused the contemporary disabled subject to emerge into discourse and social existence. These [...] practices, procedures, and policies have created, classified, codified, managed, and controlled social anomalies through which some people have been divided from others and objectified as (for instance) physically impaired, insane, handicapped, mentally ill, retarded, and deaf. Foucault argued that, in recent times, practices of division, classification, and ordering around a norm have become the primary means by which to individualize people, who come to be understood scientifically. (5-6)

The medicalization of physical difference also led to the possibility of surgical intervention, a literal example of the way that medical authority constructs the body. With regard to conjoined twins, medical documentaries present surgical intervention as the answer to anatomical otherness. Surgery can act as a form of social control in that it allows for the literal and figurative construction of bodies that 'fit' social norms. Yet, surgery also reinforces notions of superiority for non-stigmatized people by strengthening "perceptions that stigmatized people are fundamentally inferior, passive, helpless, and childlike", in need of medical care and 'repair' (Coleman 1997: 224).

Importantly, for Foucault, the inscription of power on the body is inevitable; bio-power is governmental, but it is also constitutive in the sense that it would be impossible to imagine and 'live in' a body outside of discursive norms. Conjoined twins who do not undergo surgical treatment, therefore, do not exist outside of the realm of medical discourse, which is expressed in ways that are more subtle and more difficult to challenge than the surgeon's knife. However, it is still important to tease apart technological constructions of the body, for instance through surgical means, and the social norms that these interventions support and naturalize. As Robert Blank reminds us, "[t]he assumption that we can, through these [surgical] interventions, find biomedical solutions to social problems tends

to reduce all human frailties and deficiencies to medical problems open to technological fixes" (1994: 7).

In addition to the distinction between the social and the medical, the possibilities and limitations of surgical alterations once again draw attention to the difference between the body as constructed and the body as material object, which has already been introduced in the previous chapter. While the body lends itself to discursive manipulation on the one hand, it also resists the process of transformation in its material quality, influencing and limiting what can and cannot be done with or to it. In *Deviant Bodies* (1995), Jennifer Terry and Jacqueline Urla point to the paradoxical quality of bodies; even though bodies may seem self-evident, natural and real with all its "contours, anatomical features, processes, movements, and expressions", [...] "they [also] become surfaces onto which physicians, scientists, and lay people can inscribe and project powerful cultural meanings and moral prohibitions" (6). One of the problems associated with the medical model of disability¹⁹ is that it overlooks these processes of inscription through which medical and scientific power together with social norms and ideals are affirmed. The medical model is based on an essentialist view of the body in that disability is understood as a physical problem that can be targeted and alleviated by medical authorities. The fact that surgical intervention and medical treatment also construct and reinforce norms concerning health and sickness as well as deviance and 'normalcy' is largely overlooked.

Another point of criticism that has been brought forward with regard to the medical model of disability concerns the question of agency. In his discussion of the medical model of disability, Tom Shakespeare notes, "No authors have ever explicitly affiliated themselves to [the] medical model or individual model perspective" (2006: 15), yet he also explains that

it has become a proxy for all that is wrong with traditional attitudes to disability. It stands for research and practice developed by non-disabled people, without the participation of disabled people. It stands for the dominance of professionals. It stands for the idea that disabled people are defined by their physical or intellectual deficits. It stands for medicalisation. (ibid: 18)

¹⁹ Michael Oliver uses several different terms to describe the 'medical model of disability'. He refers to the "individual model" of disability in *Social Work with Disabled People* (1983) and "personal tragedy theory" in *The Politics of Disablement* (1990).

While Shakespeare may be correct in his assessment that few writers have outspokenly embraced the medical model of disability, it cannot be overlooked since it was the medical model that activists and academics in the United Kingdom²⁰ in the late 1970s and 1980s sought to challenge. According to Michael Oliver, who is credited with coining the term ‘social model of disability’ (an oppositional model that I will discuss in detail in chapter three):

[t]he medical model of disability is one rooted in an undue emphasis on clinical diagnosis, the very nature of which is destined to lead to a partial and inhibiting view of the disabled individual. In order to understand disability as an experience, as a lived thing, we need much more than the medical ‘facts’. (1990: 48-9)

In *Disability Theory* (2008), Tobin Siebers explains, “The medical model defines disability as an individual defect lodged in the person, a defect that must be cured or eliminated if the person is to achieve full capacity as a human being” (3), and Susannah Mintz, in *Unruly Bodies* (2008), refers to a “medical paradigm” (2) that defines disability “as an affliction of the individual body (an error to be fixed by surgical or chemical intervention or overcome by rehabilitation)” (ibid). According to the logic of these closely aligned definitions, any ‘other’ body becomes a conundrum that must be analyzed and, whenever possible medically manipulated and transformed. What is perceived as most problematic about the medical model is that it naturalizes social norms by inscribing them on the body and turning them into a problem that can be solved by medical authorities, leaving little room for the patient’s voice.

Conjoined Twins as Mediated ‘Events’

This chapter examines closely the medical documentary as a medium of representation that upholds normative assumptions surrounding the anomalous body and promotes, in a variety of ways, a medical model of disability, or a view

²⁰ According to Sharon Snyder and David Mitchell, the ‘social model of disability’ “developed largely in the United Kingdom, beginning with the history of the Union of Physically Impaired Against Segregation (UPIAS). The British discourse on disability both preceded and substantively influenced U.S. models” (2006: 6). For a more detailed discussion of the history of disability studies in the United Kingdom, see Tom Shakespeare’s discussion in *Disability Rights and Wrongs* (2006) and Carol Thomas’ *Sociologies of Disability and Illness: Contested Ideas in Disability Studies and Medical Sociology* (2007).

that non-conforming bodies must be interpreted and reconstructed for the sake of 'normalcy'. Generally, when physicians are shown discussing the possibility of separation surgery for conjoined twins, they refer constantly to 'normality', and in articulating and anticipating a 'better future' for the twins, they actively encourage the assumption that any other outcome for conjoined twins renders them abnormal and 'broken'; in other words, beyond the help of surgical procedures and technology.

The medical documentary raises a number of ethical concerns. According to Sharon Mitchell and David Snyder, the genre is one of several

cultural locations of disability, in which disabled people find themselves deposited, often against their will. At the very least, each of these locales represents a saturation point of content about disability that has been produced by those who share certain beliefs about disability as an aspect of human difference (2006: 3; their emphasis).

Their main concern, which echoes Stuart Hall's, is about the entanglement of power and representation: who controls and therefore produces the images of disability. Further, medical documentaries about separation surgery performed on conjoined twins are often about children who lack the agency not only to decide whether to be separated, but also whether to share that experience with a television audience. They are, according to G. Thomas Couser, 'vulnerable subjects': "persons who are liable to exposure by someone with whom they are involved in an intimate or trust-based relationship but are unable to represent themselves in writing or to offer meaningful consent to their representation by someone else" (2004: xii). For these children, the decision to separate and televise the procedure is made by parents and doctors, "agents more powerful or privileged than themselves to hear, articulate, and act on their stories" (ibid: 16). As Couser points out, there is an inherent contradiction in situations such as these where physicians, according to professional medical ethics, must "protect the confidentiality of their patients or clients in their case histories or case reports", but are not governed by the same principles when it comes to representing their patients in forms of life writing, including medical documentaries produced for television (ibid: xi). Furthermore, the twins' story is filtered through writers and directors, who make decisions about what to include and what to edit out—how to author their story for educational and/or entertainment appeal and how to

represent them. The medical documentary is therefore constructed as it simultaneously constructs.

The appeal of medical documentaries is not just the anomalous body, which fans curiosity, but also the fascination with the medical efforts made to manage that body. This combination fuels popular 'reality' television series produced in the 2000s, such as Discovery Health Network's *Medical Incredible* and *Big Medicine* in the United States, and Channel Four's *Bodys Shock* series in the United Kingdom, which features episodes like *Born with Two Heads*, *The Boy Who Gave Birth to His Twin*, *Curse of the Mermaid*, *The Girl with Eight Limbs*, and *I am the Elephant Man*. While society may have an interest in the human body in general, there appears to be a fascination with 'othered' bodies, which is fed by television shows that claim to 'investigate' these bodies—television shows that blend reality and entertainment under the guise of education and analysis.

If, as Garland-Thomson suggests, nineteenth-century freak shows “choreographed human variation into a spectacle of bodily ‘otherness’ that united their audiences in opposition to the freaks’ aberrance and assured the onlookers that they were indeed ‘normal’”, then it seems possible that the televised medical documentary could be read as an extension of this particular kind of spectacle (1997: 17). Jose van Dijck reasons that

[t]he live freak show never really disappeared, but took on a new cloak; it evolved into medical documentary, the appeal of which is based, to a large extent, on the convergence of medical and media techniques. More than the original freak show, its most recent, mediated version involves a hybrid spectacle in which information, entertainment, public relations and ideology have fused beyond recognition. (2002)

While the fusion of medicine and media plays a major role in the appeal of medical documentaries, as van Dijck hypothesizes, their appeal can also be traced to their provision of visual confirmation of a regulatory procedure to 'correct' the different body. These documentaries do not *just* display unusually-bodied people as freak shows did; in addition, they show how “[t]he surgeon's knife is wielded in the interests of repair, restoration and sometimes regeneration” of that extraordinary body (Shildrick 2008: 32). It is not only the spectacle that provides the appeal; it is the possibility that the spectacle can be reformed, “regulat[ed] and “discipline[d] [...] so that it conforms to acceptable standards of beauty”,

according to Niall Richardson (2010: 1). With regard to conjoined twins, it is not the fact of their birth alone that warrants media attention; it is the ensuing discussion of separation and the continuing drama of the pre-surgical preparations, surgical procedure, and outcome that maintains interest. To borrow a phrase from Leslie Fiedler, conjoined twins have become "events" (1978: 197). The idea that surgeons are attempting what is viewed as clinically impossible—stretching their skills, knowledge, and medical technology to the limits to repair that which nature supposedly has failed to form correctly; the very notion that they are attempting the surgery in order to “alleviate [...] the suffering of these kinds of people” is what ultimately compels people to watch (Dreger 2000: 169).

Surgeons, in their quest to restore ‘normality,’ are therefore presented as heroes, rescuing their morphologically challenged patients from their entrapment within a body that is far from ideal, from a body that allegedly limits their ability to interact with and participate fully in the world. Myser and Clark maintain

that medical documentaries are especially vivid instances of the correlation of power and knowledge [in that they] inherit and reiterate certain 'regulatory ideals' in their narrative and imagery, and that such ideals act—in the hands of surgeons represented there—to determine and even (re)shape the 'monstrous' difference of extraordinary corporeality with cutting, sometimes killing force. (1998: 46)

As a “technology of representation”, the medical documentary reinforces cultural norms, pitting the 'normative' body against the body that is represented as and in crisis (van Dijck 2005: 11). They present the potentially destructive idea that the 'abnormal' body should be transformed at all costs.

Despite the fact that the corrective imperative fundamental to medical documentaries is missing in the historical freak show, medical documentaries nevertheless use many of the same tactics as freak shows to spectacularize ‘other’ bodies. Garland-Thomson suggests: “So voracious and potentially dangerous is curious looking that only a respectable goal rescues it from our uneasiness” (2009: 63). Like the freak show, medical documentaries justify the curious stare by presenting the anomalous body within a framework that is meant to be 'educational' (in the sense that it is based upon a scientific and medical premise). Freak show managers distributed photographs and drawings of their exhibits and used technical explanations by doctors and scientists to explain to the viewer

exactly what they were seeing. Similarly, the medical documentary showcases the myriad sophisticated medical imaging tools (including x-ray, CAT scans and MRI scans) that are used to make the body transparent and visibly open to the doctor and spectator, even before the surgical cut. The invasive and potentially voyeuristic quality of the clinical gaze is authorized by the medical framework, which promises to educate the viewer and alleviate suffering. As a result, the viewers "[have] no reason to be ashamed of their voyeurism; after all, the medical scans legitimate the spectacle" (van Dijck 2002: 550).

In addition, the potential uneasiness felt when confronting the unusual body is alleviated through the widening of physical space between spectacle and spectator, which serves to differentiate the freak show from medical documentary. A viewer is less likely to feel uncomfortable about staring when he or she watches a televised program from the comfort of a private space, rather than in an open, public space, where the encounter with the freak is direct and unmediated. According to Sally Chivers and Nicole Markotic, "In front of a screen—in an audience-directed cinema or individually at home—lies a space for a normative and deviant public not just to look but to *stare* at disabled figures without censure" (2010: 4; their emphasis). Unlike the nineteenth-century spectator, the modern-day television viewer does not have to manage a potentially uncomfortable visual exchange and is provided instead with a "perfectly panoptic vantage point, freeing him and her to look at will [...]" (Clark and Myser 1996: 343). In turn, the line between viewer and medical expert is reduced because the viewer is invited to share the clinical gaze; the surgeon brings the viewer into the closed realm of the patient's body, permitting him or her to share privileged information and explore its "depthless surface" (ibid: 345)—to see what the surgeon sees: a "disembodied body [that] is infinitely compliant and hollow, a docile ensemble awaiting not only its reconfiguration but also its reanimation by the physicians' touch" (ibid). In examining the image, which has been determined by medical technologies, viewers are implicated in the potential transformation of conjoined twins. The "panopticon voyeur" (2010: 4), to borrow a term from Chivers and Markotic, "straddles a position between passive observer and normalizing surveyor" (ibid).

Since "[t]ransparency has come to connote perfectibility, modifiability, and control over human physiology," the pliability of the body is dependent on its complete visual availability (Clark and Myser 1996: 345). Importantly, the clinical gaze not only makes available this body, but also legitimates its correction and therefore needs to be understood as active rather than passive in that it presents a specific view of the unusual body as a body in need of correction. As Donna Haraway has stated,

The 'eyes' made available in modern technological sciences shatter any idea of passive vision; these prosthetic devices show us that all eyes, including our own organic ones, are active perceptual systems, building on translations and specific ways of seeing, that is, ways of life. There is no unmediated photograph or passive camera obscura in scientific accounts of bodies [...]; there are only highly specific visual possibilities, each with a wonderfully detailed, active, partial way of organizing worlds". (1997: 285-6; her emphasis)

In medical documentaries, the 'eyes' of the technological devices that open the body for interpretation seek to reinforce norms of health. In using scans and photographs to show what is disordered about the body, an ideal is automatically posited as the opposite of what doctors (and viewers, by extension) are witnessing; medical images offer a specific and inevitably one-sided view of the body: a view of 'possibility', as Haraway states. When viewers observe representations of a 'broken' body, they are encouraged to attach to it not just the possibility of repair offered by medicine, but also all of the alleged privileges that a life of physical 'normality' can offer. If "staring both registers and demands a response" (2006: 174), then televised medical documentary is endowed with a certain amount of power in that dynamic exchange; if a viewer, as Garland-Thomson suggests, is "search[ing] for narratives that impose coherence on what appears to be randomness in our experience of the world", then it would logically follow that medical documentaries actively shape our idea of what it means to be 'normal' (ibid). In other words, medical documentaries "function in prescriptive ways, reproducing normative assumptions about what it means to be properly embodied" (Myser and Clark 1998: 2).

In the case of conjoined twins, medical images lay bare individual parts of a lived body and emphasize normalization when, according to Jana Sawicki, "there may be better ways of defining the problem. There is the danger that medical

solutions will become the only ones and that other ways of defining them will be eclipsed" (1999: 195). In other words, scans confirm the potential of the fused body to be cut into two separate bodies and serve as a translation of the desires of a society that does not readily or easily accommodate bodily difference. They facilitate the idea that bodies on a monitor can be changed or altered and imply that there is the potential of a different and better future for conjoined twins. Thus, the clinical gaze is self-legitimizing: it constructs a medical problem only to offer a solution. In turn, it authorizes the fascination associated with viewing 'other' bodies at the same time as it reinforces ideals of 'normalcy'.

The role of the viewer in this context is complex. Jacques Rancière, whose theories of aesthetics have been widely used to study the visual arts, identifies the spectator as an equal in the spectator/actor dynamic. In *The Emancipated Spectator* (2009), Rancière unsettles the "opposition between viewing and acting", positioning the spectator as an agent who also acts; "like the pupil or scholar, [s]he observes, selects, compares, interprets. She links what she sees to a host of other things that she has seen" (13; *ibid*). Applying this concept to the dynamic of the medical documentary, it would follow that at the very instant a viewer stares at the body on the screen, whether shot by the camera, via imaging tools, or represented by medical models, he or she is included in the normative transformation that is being articulated. Viewers are not just viewers; they are also participants in the normalizing clinical process because they attach all of their past knowledge and all of their own ideals to the 'disordered' body. Similar to Hall, who argues that objects and events lack meaningful existence until they are represented, Chivers and Markotic maintain that "representation of disability does not exist separate from disability itself. Accordingly, [they] propose that—disabled or not—when 'we' all watch a film, we all participate in disability discourse" (2010: 4). Here, representation is constitutive of disability. This means, of course, that the viewer can also resist ideals of 'normalcy' and surgical solutions offered in the documentary. He or she can accept them passively, but if the viewer—as Rancière has it—is an active agent in the reception of these ideas, then he or she also has the potential to resist or subvert them.

The Evolution of Medical Documentary

To better understand the workings of medical documentaries, it is important to acknowledge documentary as a hybrid genre. In "Toward a Poetics of Documentary," (1993) Michael Renov argues that there are four discursive functions of documentary (preservation, persuasion, analysis, and expressivity²¹) but that any poetics of value "must be willing to acknowledge transgressiveness as the very *condition* of textual potency" (25; his emphasis). This transgression of the borders between documentary and fiction is attributable to two trends, according to Kevin Macdonald and Mark Cousins: "the desire to make films which although educational and informative are also unashamedly entertaining" (1996: 311) and "a willingness to challenge the boundaries between 'documentary' and 'fiction'" (ibid). Thus while documentary aims to instruct and record 'real' events, entertainment informs every aspect of its production; the fictional and factual are often blurred in the bid to achieve certain results, for instance, to create a compelling story.

With regard to medical documentaries more specifically, Catherine Belling argues, "an operation shown on television has been placed in an interdisciplinary domain where spectacle and storytelling overlap with the material effects of surgery on actual bodies" (1998: 1). Medical documentaries, then, are "an almost indistinguishable mixture of the scientific and the literary, of actuality and artifice" (ibid: 3); they "[contain] any number of 'fictive' elements, moments at which a presumably objective representation of the world encounters the necessity of creative intervention" (Renov 1993: 2). In his introduction to *Theorizing Documentary*, Renov includes construction of character, the use of poetic language, narration, musical accompaniment, creation of suspense, dramatic arcs, the use of high or low camera angles, close-ups, telephoto or wide-angle lenses, and use of editing in the list of representational tools through which documentary 'reality' is constructed (ibid: 2-3). What becomes apparent here is that Haraway's remark about the power of the modern technological 'eye' applies not just to the medical technologies represented in the documentaries, but also to the television

²¹ Kevin Macdonald and Mark Cousins describe the forms of documentary as "the observational, poetic, essayistic, investigative or explorational" in *Imagining Reality: The Faber Book of the Documentary* (1996: 311).

camera itself as a partial and subjective eye: the camera is a tool through which 'reality' is shaped and ideology is transferred. In light of this insight, and following the logic of Stuart Hall, what we take in from television—the images, sounds, etc—constitutes language, and language

operates as a *representational system*. In language, we use signs and symbols [...] to stand for or represent to other people our concepts, ideas and feelings. Language is one of the 'media' through which thoughts, ideas and feelings are represented in culture. Representation through language is therefore central to the processes by which meaning is produced. (1997:1, his emphasis)

It is also important to note that medical documentaries evolved from the practice of taping surgical procedures so that other surgeons and medical professionals could learn from them. This practice began with individual surgeons who used the tapes for instruction, but "after 1945, hospitals and professional medical organizations took charge of producing these films" (van Dijck 2002: 542). Then, between 1950 and 1970, according to van Dijck, film was gradually replaced by television. This move to television was not just a change in medium but also—more importantly—a change in audience. In this medium, medical documentaries were sponsored more and more by pharmaceutical companies who had a financial interest in their success. Today, "public and commercial broadcast companies have become involved in their production and distribution" (ibid). This is testimony to the fact that medical documentaries have become to a large extent about entertainment and profit and, in these respects, they are similar to freak shows of the nineteenth century.

Medical Documentaries and the Anticipation of 'Normalcy'

It is no small irony that televised surgeries inevitably further the spectacle of the conjoined twins' body, which is of interest precisely because of its physical difference, even though they are undertaken for the sake of normalization. In particular, medical documentary "stages the spectacle it purports to describe" by employing what I will refer to in this chapter as the 'moment when'—the anticipated recognizable and positive outcome of a normalizing procedure (Clark and Myser 1996: 338). The way such appeals to futurity can serve to solidify social

norms has been described in *No Future* (2004), in which queer theorist Lee Edelman identifies and challenges the ways that political discourse relies on “futurism's unquestioned good” (7). Countering what he calls reproductive futurism, he argues in favor of the denial of “a constantly anticipated future reality” (ibid: 8-9), which is an imaginary construct that only serves to reaffirm our subject positions and belief systems in the present: it is “reality in the form of fantasy: the fantasy, precisely, of form as such, of an order, an organization, that assures the stability of our identities as subjects” (ibid: 7). Edelman's advocacy of a non-future oriented stance serves to upset the privilege of reproductive futurism, which in his reading, favors heteronormativity. Reproductive futurism is not identical with the future-oriented cure narratives discussed in this chapter, but Edelman's work draws attention to the way in which social norms are reinforced through an appeal to futurity, especially with regard to the figure of the Child. In this sense, his work is useful in a discussion of non-normative bodies. Just as politics, at its conservative core, works to “*affirm* a structure, to *authenticate* social order” through a sentimental “fight for our future/'fight for our children'”, so, too, do medicine and society in general aim to ‘restore order’ to nonconforming bodies through normalizing procedures (ibid: 3; his emphasis). More specifically, in medical documentaries, surgeons and parents hope for and express the desire for a redemptive future, built upon the image of the (normal) child as the “perpetual horizon” toward which any intervention is directed (ibid: 3). In the case of conjoined twins, surgical intervention is justified because it is undertaken to create a future for children who, supposedly, would not have one without medical treatment. Moreover, as the discussions in chapters three and five show, heteronormativity is often implicated in future-oriented narratives about conjoinment, as physical ‘normalcy’ is associated with heteronormative ideals including a monogamous heterosexual relationship, marriage and reproduction.

With regard to conjoined twins, this chapter shows how a future moment both frames and drives the narrative of the medical documentary, legitimizing surgical intervention and reinforcing ideals of physical ‘normalcy’. The constant reiteration of the ‘moment when’ a body in crisis most closely aligns with the idea of a ‘normal’ body is the tool with which medical documentary actively constructs

and sustains a normative body. As a narrative of becoming, the medical documentary emphasizes the journey, anticipating an elusive future in which those with unusual anatomies are necessarily ‘rescued’ from their bodily entrapment. Thus the future is always iterated as an improvement; it corrects the failure of the past (in the case of conjoined twins, the failure of the egg to fully split in the womb²²) and the failure of the present (the failure of the body of conjoined twins to conform to a normative standard of appearance). ‘Normalcy’ is the end result toward which conjoined twins are compelled and which the medical documentary constantly (re-)articulates; it is the hoped-for ending that guarantees not only a cloak of social invisibility, but also acceptance. In *Psychological Profiles of Conjoined Twins* (1988), J. David Smith argues that “[m]edical advances have enabled parents of these children to anticipate with optimism the possibility of longer and more normalized lives for their conjoined infants” (57). Considering the overlap of medical and media technological advances, it follows that medical documentaries perform the optimism that medical advances have assured.

Before discussing any specific documentary, it is necessary to clarify that the aim of this chapter is not to judge the decisions made by families and doctors to separate conjoined twins nor to make any value statement about their motives. My goal is to examine and evaluate the ways that these cases are represented in a way that directly reinforces the ‘ideal’ body. My aim is to examine the medical documentary as a site of representation, a genre that (re)shapes the body of conjoined twins through a constant articulation of a desired effect or future result. In *Queer Optimism: Lyric Personhood and Other Felicitous Persuasions* (2008), Michael Snedicker contends, “Hope is promissory; hope is a horizon” (16); in these documentaries, hope for the ‘moment when’ is the trope that impels the narrative. I recognize that comments and footage have likely been edited to achieve this desired effect. I also agree with Richardson, who states that today’s spectators

²² This refers to the fission theory of conjoined twins—the most readily accepted theory that two identical twins that fail to completely separate result in conjoined twins. There is however another theory, which states that conjoined twinning occurs as a result of fusion. This theory, which is just beginning to emerge as a logical explanation, states that conjoined twins are the result of stem cells from one twin adhering to stem cells of the other. For a detailed account of the fusion theory, see *Conjoined Twins: Developmental Malformations and Clinical Implications* (2003) by Rowena Spencer.

“are certainly aware of the art of re-presentation—whether or not they are going to articulate their understanding in such terms” (2010: 6). I do, however, believe that a distinction must be made in terms of a contemporary viewer’s experience of documentary and other genres such as popular film and ‘reality’ television, since documentary positions itself as educational and informative and thereby lays greater claim to a ‘truthful’ depiction of reality. This is not to say that viewers fail to understand documentary as *representation*, but it may mean that far more viewers overlook the same conventions that they might otherwise question more readily because they are watching a medical documentary that is shown on a reputable television network.

Ultimately, one of the aims of this chapter is to demonstrate that documentary is a carefully orchestrated form of representation that tends to adhere to the medical model of disability, presenting the body of conjoined twins as a purely bio-technical problem that must be resolved through surgical means. Therefore, medical documentary is also a filter through which viewers potentially become implicated in the surgical cut and the idealization of normative bodies. At the same time, I also explore in this and subsequent chapters the ways in which representations of the figure of conjoined twins open up to criticism the norms and ideals perpetuated through the medical model of disability.

Kendra and Maliyah Herrin: “Separating Conjoined Twins”

The 15-minute *20/20* segment, “Separating Conjoined Twins”, that aired on August 11, 2006, just days after Kendra and Maliyah Herrin were separated, provides an example. Born in 2002, the former Ischiopagus/Omphalopagus²³ twins lived conjoined for four years prior to their separation surgery at Primary Children’s Medical Center. When they were born, their parents decided against surgery not only because the odds that both girls would survive were only 20%, but also because the girls were healthy and functional. In fact, the family’s website claims that “Together they could scoot around, roll over, pull up to standing, and even do a summersault (sic)” (Herrin and Herrin).

²³ Ischiopagus / Omphalopagus refers to twins who are joined at the abdomen, from the sternum to the groin, with spines that form a Y-shape.

By the time the twins were four years old, however, their parents had decided that surgery, which would leave Maliyah without a kidney until she could receive one from her mother²⁴, was in their best interest, especially since doctors estimated their odds of survival at 95%. In the 20/20 segment, Erin Herrin tells interviewer Deborah Roberts that the decision was not an easy one. In fact, she explains that her husband and she continued to “flip-flop” when discussing separation: “They’re healthy. They’re safe right now. We can keep them together, or we can separate them, and give them the best chance possible of leading separate lives”. In this instance, Erin’s response shows no recognition of the unique form of individuality and personhood the girls have come to know in their shared body.

Yet, other parts of the interview reveal a more ambivalent view towards separation surgery. When Roberts asks Jake and Erin whether they had ever asked the girls if they wanted to be separated, Jake says, “They seem to see themselves as being separate when they got older, but they were scared of the process of going through it”. His statement is difficult to read, as viewers do not know whether Kendra and Maliyah were ever asked about their opinions concerning separation surgery. What they might have said in response to this question remains unclear and the viewer only finds out what they ‘seem’ to think of their situation²⁵. Furthermore, the girls’ expression of fear is worth noting, since the viewer is not told whether it is physical pain they fear or what life will be like for them following the surgery, when they have to relearn how to function physically and socially in separate bodies. Even their father shows anxiety about life post-separation when he explains that the surgery is bittersweet and that “[he’s] just going to miss it” (ibid), presumably referring to the girls’ physical conjoinment and the life they have lived together so far. This ‘mourning’ is also reported on August 6, 2006, one day before the surgery, in one of the daily updates on the family website: “We are doing well, although shedding many tears

²⁴ Maliyah received a kidney from her mother in 2007.

²⁵ While the documentary does not discuss at any length the decision to undertake the surgery, or what the girls thought about being separated, Erin Herrin discusses this in her own book, *When Hearts Conjoin* (2009). She writes, “In the end, it was Maliyah and Kendra who helped us finalize our decision. Of course, we would never let them make the decision, because if something went wrong with either one of them, they would feel responsible. That burden needed to fall on me and Jake alone. We discussed the surgery with the two of them, and what kinds of changes it would mean in their lives. We wanted to know what they wanted and how they saw themselves” (136).

today. Not so much because we are scared or nervous, but because we are mourning their last day conjoined” (Herrin and Herrin). The girls have clearly become an integral part of their family as they are—a point that is made more poignant by intermittent scenes in the *20/20* segment of them doing conjoined what many other singleton children do: playing princess, going to the zoo, playing in the pool with their siblings and parents, and taking turns doing activities they want to do. On the one hand, filming the girls taking part in ‘normal’ activities puts even greater emphasis on their physical difference, since it encourages comparisons with other clichéd depictions of non-conjoined children in similar situations. On the other hand, these images also demonstrate that the girls can physically and socially live a ‘normal’ life despite their physical difference. Although the family’s various statements indicate anxieties about the surgical procedure, in keeping with the medical model of disability, the possibility that surgery is not necessarily required and that there might be other non-surgical ways of dealing with the girls’ condition is not explored.

The medical documentary’s focus on the strictly physical aspects of conjoinment becomes apparent later in the segment. Viewers are reminded that the girls’ surgery is rare because they are older than most children who undergo separation. They must therefore be prepared mentally for what is to come. To assist the girls in this process, the hospital provides each twin with her own set of stitched-together rag dolls that each can separate when she is ready. Just a few days before their surgery, Kendra decides to separate her dolls, cutting the stitch with a pair of scissors, but Roberts explains that “Maliyah, perhaps realizing that she has the most to lose, isn’t ready yet”. Maliyah’s fear of separating her dolls might stem from her inability to imagine or predict what life will be like post-surgery. Both girls will have to redefine themselves as singletons, and their family will have to re-evaluate their relationship with the girls, but these psychosocial processes are not given much attention in the documentary. Similarly, the parents tell the girls “everything their four year old minds [can] absorb about the process”, but this mainly entails the *physical* changes the twins are about to undergo. Maliyah says that she does not have a kidney in her back, and Kendra adds that her sister will be going to dialysis. They also know that they are going to stay in the hospital “for a long, long time”. The twins are clearly informed about what will

happen to their bodies, but there is little evidence in this documentary that they are being prepared to handle the psychosocial demands of being apart. This is compounded when, during a scene with the surgical team, Dr. Rebecka Meyers, the head of the surgical team, asks, "Anybody else have any non-xray, non-surgery issues"? This establishes at least the possibility that there might be more to this separation than technical issues, but even though a voice is heard from among the table of professionals, the documentary skips over the question and moves on to the next scene, thereby diminishing its importance. Instead of exploring possible 'non-surgery issues', the program cuts back to an interview with Meyers, wherein she explains the girls' physiology and how their bodies will be separated and reconstructed. She says, "Essentially from the waist down, they are one child, and from the waist up they're two children, and our job as surgeons is to find how to make them two children from head to toe". This strong emphasis on the girls' physical condition rather than psychological or social questions leaves unchallenged the norms that are being naturalized through the surgical cut: the idea that two bodies equal two individuals.

While this logic is upheld by the segment, the Herrin blog reveals that the aftermath of the surgery is much more complicated:

August 7, 2006: Well, the girls have just been as stable as can be. The nurses said their vital signs have followed each other, like when Kendra's heart rate goes up, so does Maliyah's. So we know they still have a huge connection, it's just not physical anymore.

August 11, 2006: Just wanted to give a quick update about something funny with the girls. At first Maliyah was behind Kendra on when she would come off the ventilators, now Maliyah is ahead of Kendra. We are looking for Kendra to rally though. They are probably trying to have a little race between them, it wouldn't surprise us if it ends in a tie. Actually that's what we're hoping. Also Maliyah has turned on her side and is now laying the way she was conjoined. It is quite sweet, but that is the way she feels most comfortable.

August 17, 2006: Kendra has started to ask why Maliyah isn't "stuck to me" anymore, so we have just reminded her about what we talked about before surgery, and she seems ok with it. Although she says she misses her. But we told her that once they are all better, they can get in the same bed and even pretend they're still stuck together. She gave us a huge grin when we told her that.

August 22, 2006: Kendra is just going along like nothing's wrong. She asks about Maliyah sometimes and talks about how she was "cut apart". But she is as happy as can be. We can't wait until Maliyah is back to herself so K&M can feed off each other. We were saying last night how cute Kendra is, but she's not Kendra without Maliyah. Their outgoing natures feed from each other. We can't wait to see that again. (Herrin and Herrin)

Each of these entries from the family's website confirms the significance of non-physical aspects of conjoinment, which are not acknowledged in the *20/20* segment. The first entry is contradictory: the beginning of the update points to a connection between Kendra and Maliyah that cannot be explained fully through their physical conjoinment, as the girls' bodily rhythms match despite the fact that they have been surgically separated. The closing statement of this entry, however, asserts that being conjoined was merely a physical connection that no longer exists post-surgery. In the second update, the parents again hint at a psychological connection between the girls, both in the way they 'race' each other subconsciously, and in the fact that Maliyah reverts to her position of conjoinment for comfort. The third entry confirms that Kendra does not fully understand what has happened to her; she misses her sister and looks forward to being 'stuck together' again. Finally, in the last update, Erin says that Kendra is not truly Kendra unless she is with Maliyah. All of these statements on the website counter the emphasis of the segment, which is exclusively on the physical nature of the split. They show that, for their family at least, the girls' conjoinment continues to exist on a psychological and emotional level, creating complexities that cannot be solved easily through surgical means. Moreover, the blog entries indicate that the family continues to draw on the girls' past conjoinment to make sense of their post-surgical condition; the relatives, too, are not able to stop thinking about the twins in terms of conjoinment only because their physical condition has been altered. The information about the Herrin twins provided by their own family outside of the *20/20* segment thus help to problematize the exclusive representation of the purely physical aspects of conjoinment promoted in the documentary itself.

Given that the girls were healthy and functional despite their conjoinment, as the parents acknowledge and the footage shows, it is important to ask what motivates the decision to choose surgery. This is where the future-oriented desire

for the ‘moment when’ comes in, which legitimates separation surgery. In the documentary, Erin explains that she has chosen separation to “give them the best chance possible of leading separate lives” and Dr. Meyers, in an interview after the surgery, states that during the surgery she “feels all of the pressure of all of the anticipation, the parents counting on you, and the girls counting on you, and the world watching you”. Once it is announced that the girls have been separated, Jake proclaims, “Our babies are born.” Moreover, throughout the operation, the Herrin family website was updated to reflect the girls’ progress. On August 8, 2006, the following update was issued:

A press conference was held at approximately 12:30A.M. with many various news teams there asking questions about how Jake & Erin have been holding up throughout the day and what was going through their minds when news came that the separation was complete. They were also asked about the future of the girls and how things like school proms might affect them. Erin responded by saying that things like that were now going to be possible. (Herrin and Herrin)

The implication here is that the girls will, only after surgery, be able to enjoy the privileges that come with social acceptance; constructing two bodies from one will allow Kendra and Maliyah to experience ‘normal’ activities in the future like going to proms, which signifies leading a full social and possibly romantic life. The surgery is a means through which their ‘problematic’ bodies can be repaired, opening up the possibility of a more ‘normal’ future.

Importantly, however, surgery does not offer the ‘moment when’ physical ‘normalcy’ is attained. The short documentary, in fact, ends abruptly. Viewers are told that the girls are recovering, and that it will be several weeks before they can think about a kidney transplant for Maliyah. The final image viewers see of the girls is of them lying in separate beds. Because the documentary has been built around the possibility of a ‘normal’ future obtainable through surgery, one might imagine that this goal has been achieved, because the separation has been successful. Their family’s website, however, reveals a more complicated outcome, not just for the girls, but also for the family as a whole. On August 9, 2006, just a few days after the surgery, the Herrins reported that their older daughter Courtney was having difficulty with the separation: “Courtney got to see them yesterday. She did so well and was so strong. But later that night she cried about missing them the way that they were. We told her that it was ok to feel like that

because we did too. But we said that they would be able to do more with her once they got better” (Herrin and Herrin).

Further, over four years after the surgery, the twins deal with impairments that include prosthetic legs, and they have recurring health problems. On May 3, 2010, a status update on the Herrin Twins’ Facebook page announced, “Tomorrow Maliyah is getting her broviac²⁶ out. We are sad to see it go because it was saving her a lot of pain from the blood draws. Now its (sic) back to the hospital probably weekly again. It was a great vacation!! :) (Erin)”, and a month earlier, on April 12, 2010, they announced: “WE went a WHOLE week without going to the hospital. That is a record!!” (Herrin; “Herrin Twins Posting”). In February of 2010, just six days apart, the following updates appeared on the “Herrin Twins” Facebook page:

04 February at 10:12: Maliyah has been in the hospital since Monday. We thought she was rejecting her kidney. Things are getting better now.

10 February at 18:16: Kendra is going in for surgery tomorrow. She needs to get her broviac(sp) out, we are finally done with her IV antibiotics. She also will have some other things done. She will be home same day, I hope. Last time Kendra stopped breathing when she was waking up. They took her to the ICU for that. Please pray everything goes well tomorrow and she is safe!!!! (ibid).

This is representative of the long list of health problems, both innocuous and serious, that Kendra and Maliyah’s parents have described on the social networking site. Thus, the case of the Herrin twins raises the question of whether separation surgery has fulfilled the promise of a better quality of life. It is also left open whether each girl’s sense of herself as an individual has been enhanced by the physical separation.

My goal has not been to provide a definitive answer to either of these questions, but rather to highlight the ways in which the twins’ separation has been constructed by a news program as a success—simply because it resulted in two separate bodies—and how that success is problematized fundamentally by the family’s own accounts of the same events. The *20/20* segment upholds the regulatory ideal of the subject as one self in one body while also playing into the medical model of disability by reinforcing the notion that different bodies can and should be ‘repaired’ in the name of ‘normalcy’. The family’s own accounts of the

²⁶ A Broviac is the brand-name of an external catheter that is inserted for long-term use.

separation, however, reveal that the girls' conjoinment was an integral component of each twin's sense of self and point to the complications associated with surgery. Here, different representations of the same events serve to highlight that the medical model of disability adopted in the documentary reinforces certain norms and ideals that fail to do justice to the complexities of physical difference and its relation to questions of subjectivity.

Carl and Clarence Aguirre: *Conjoined Twins: High Stakes Surgery*

Even though she was poor, Arlene vowed that somehow she'd make her way to wherever her sons stood the best chance for success. She believed that that place was the United States. [...] And so began her *journey of hope*. (Williams; my emphasis)

The same regulatory techniques used in the brief *20/20* segment on Kendra and Maliyah Herrin are also employed in the full-length medical documentary, *Conjoined Twins: High Stakes Surgery* (Williams 2004). On several occasions, Ann Curry, the narrator of the piece, refers to the separation of Carl and Clarence Aguirre, craniopagus²⁷ conjoined twins who were brought in 2003 from the Philippines to the Children's Hospital of Montefiore to undergo four surgical separation procedures, as a 'journey of hope'. Produced by Carol Williams for NBC News Productions and aired on both Dateline NBC and the Discovery Health Channel in the USA, this documentary presents the twins' journey to 'normalcy'.

The film leaves no question that the nature of their conjoinment had limited the boys' physical and social development up to the point at which they arrived in the United States. Joined at the top of their heads, they remained for the most part on their backs, unable to develop fully either the muscle tone or coordination needed for movement. In addition, the boys arrived in New York undernourished and underweight, not because of poor treatment, but because they were aspirating the majority of the food they were given. Since moving Carl and Clarence was a two-person job, they did not get the same opportunities to interact with the world around them; any contact with people beyond their family was almost non-existent. As a result, their cognitive and language skills were

²⁷ Craniopagus refers to twins joined only at the head.

delayed as well. Due to the fact that their unique physicality, without the necessary support, was an impediment, their mother sought assistance from medical specialists, who decided ultimately to handle the case without compensation.

The documentary presents the boys' life as a progressive narrative leading up to the moment of surgery when their value as subjects will finally be affirmed. In other words, the twins' present status is constantly devalued through the articulation of a future potential that can only be achieved through separation. Their body does not count in the present because it is viewed as incomplete, lacking definition and therefore meaning; it will only make sense in the future, when it has been re-ordered and defined clearly by medical technology and the surgical cut. Through this anticipation of the cut, the medical documentary upholds the normative logic that a body must conform to physical norms if it is meant to hold meaning. In their state of conjoinment, the boys decidedly fail to matter as subjects. Using this failure as a starting point, the documentary emphasizes the 'journey of hope' that will end with two bodies representing two distinct subjects. Thus, the future is constructed as a site of determinacy and order, manifested in two separate bodies and two separate subjects: two 'normal' children. Through an evocation of this future, the twins' bodily indeterminacy is relinquished to a past that can be left behind through physical separation. This constant delay of meaning drives the narrative of the documentary "in which meaning succeeds in revealing itself--as *itself*--through time" (Edelman 2004: 4, his emphasis).

This constant articulation of, and hope for, a better future, obscures the possible complications that might arise on the twins' 'journey of hope'. In keeping with the medical model that tends to view disability as an exclusively physical problem, the documentary fails to acknowledge the possible psychological effects of surgery, and it does not challenge social norms regarding physical difference. Moreover, it tends to idealize surgery since it does not ask whether further physical and mental impairments the boys could face as a result of surgical intervention might be worse than their present conjoinment. Also, there is no discussion of how the family will be able to afford their long-term care even though it is made clear early in the documentary that the boys are from an

impoverished area of the Philippines and that both their mother and grandmother have had to quit their jobs to care for the boys.

Early in the documentary, the viewer is encouraged to invest in the boys' future as separate individuals. Broken into four main segments, the documentary begins with a brief introductory piece during which Curry gives a basic overview of what viewers will see over the next hour. The camera constantly shifts its angle, from looking down on the boys (perhaps to symbolize the isolating effect of their unique condition) to recording them at eye level as if to create a deeper sense of intimacy and connection between the viewer and Carl and Clarence. Most importantly, the film is edited to show, at first, sweeping views of the two boys in one frame with a particular emphasis on the physical site of their conjoinment and then a single shot of each boy when Curry mentions 'separate lives'. This progression of edited shots anticipates and presents as necessary the boys' journey from conjoinment to separation.

A description of the Aguierre twins as "two tiny brothers, conjoined twins, who may become giant pioneers living separate lives in a revolutionary new way" reinforces the need for surgical intervention. However, the statement is deeply ironic, as it implies subversion and agency on the twins' parts. The term 'pioneers' implies a transitory existence; it presupposes someone who is actively trying to escape their current situation to create a better life for themselves. Thus, it immediately positions Carl and Clarence as agents of change when in reality their roles are passive. As the introductory segment closes, viewers are reminded that they are watching "two brave boys, just two years old". The reference to conjoined twins as 'brave' is a description that Alice Dreger finds both common and troubling in narratives about separation, as the implication is that the children are active agents in choosing surgery:

Separations are not simply battles against unmitigated evils, and an infant cannot possibly choose such an undertaking. [...] We must not forget that the decision maker in virtually all these cases is a person who lacks first-hand knowledge of the condition, who will not undergo the procedure, who will not suffer the costs and bear the risks. (2004: 59).

Moreover, being a pioneer applies to individuals who find new and often subversive ways of living their lives *against* social norms when the twins' surgery is undertaken precisely in the name of 'normalcy'. Dr. James Goodrich, Director of

Neurosurgery at the Children's Hospital, for instance, explains: "The purpose [of the surgeries] is to get two independent children so that they can grow up to be just like any kid out there on the block". His statement does not acknowledge the boys' embodied subjectivity, which "relies on an understanding of selfhood as constituted equally through a substantive materiality and through an attention to affect, beliefs, and values" (Shildrick 2008: 31). Focusing only on the materiality of the twins' bodies, his statement upholds the Cartesian model; in cutting two bodies from one, he presumes that two separate boys will become two happy, whole, and well-adjusted boys. 'Normal' bodied—"predictable, well-ordered and functional within a narrow set of parameters that reflect only the bodily capacities of the majority"—is how Dr. Goodrich envisions the boys in the future (ibid: 33). Indeed, it is the only possible future the documentary presents for the two boys.

At this point, Curry refers to the journey that viewers will take "inside the operating room for this attempted medical first" as a surgical adventure that will facilitate the twins' journey to bodily independence. The potential dangers and risks of the surgical efforts are staged through a series of images that are not arranged chronologically: an image of the boys going into surgery fades to one of them at birth, then changes to one of them lying still on a gurney heavily bandaged at the site of their connection post-surgery, and then to a shot inside the surgical theater where Dr. Goodrich, looking down on the boys' open skulls, asks whether "anyone knows what the hell's going on in here". To heighten this sense of danger, viewers are reminded that surgeons are relying on "cutting edge science" and "a mother relies on prayer" to bring the process of separation to fruition. Then the images fade altogether, replaced by part of an interview Curry conducts with Arlene Aguirre, the boys' mother. Curry asks Aguirre what her greatest fear is, to which she replies "losing one of them". Here, death is mentioned for the first time as a possibility for the twins. In creating a sense of the danger and uncertain outcome of the story/surgery and by emphasizing the potential complications of the journey, the documentary's entertainment value, along with narrative suspense, are assured. The possible risks involved in separation surgery feed into the question that will drive the rest of the documentary: "Can doctors give them the ultimate gift?"—a future in which they are 'better' than they are now. The final sentence once again points to the teleological trajectory of the narrative in that it

anticipates a 'happy' ending for the boys, a future reality that is marked by physical separation and 'normalcy'.

Following the introductory piece, the first of the documentary's four main segments opens to a variety of images of the boys and a voiceover of Aguirre expressing the desire that drives the documentary: "I'm hoping I can see them running, walking, just like a normal babies (sic)". Again, there is an articulation of hope; it is the image of the 'normal' child to which their mother clings and which the documentary is building through successive scenes. This is not just the story of Carl and Clarence, but the story of "a courageous mother, willing to risk everything, who ventured beyond her rural island in the Philippines, to travel halfway around the world resolved to undo what nature had cruelly imposed: two handsome twin boys, joined at the head". It is also, as Curry explains, the story "of two unlikely doctors who are trying to help her quest by attempting a series of dangerous surgeries—the kind which they had never performed before". They will "test the very limits of medical advancement and try to make medical history". The trope of pioneering is rehearsed again, but this time, it is the boys' mother and their surgeons who are presented as breaking new ground and acting heroically to bring the twins (and the viewer) closer to the 'moment when' they will become two individually-bodied boys.

The boys' role is largely passive. As is typical of the medical documentary genre, the 'periphery' takes center stage: the medical staff who are attempting the impossible become the story's focus; it is they who will succeed or fail and who have the potential to help the boys. In turn, the body of the twins is reduced to a vehicle through which medical authority can exert its power. In her examination of the televised operation of two-year-old conjoined Thai sisters, Dao and Duan, van Dijck notes an evolution in the medical documentary from the 1990s onward, which is readily apparent here. She contends that recent documentaries rely on a human-interest angle (presenting the patient as a real person with a story and the surgeons as empathetic saviors) to increase the "narrative and dramatic appeal" (2002: 549) of the program but that this angle is often used to disguise the professional and commercial benefit of the documentary:

Televised operations [...] are an excellent frame in which to promote the skills, interests and advancements of the medical profession and the eagerness of hospitals and professional organizations to cooperate with

television companies underscores the promotional relevance of these programs for elevating the status and prestige of their field. The interest of surgeons to attract attention for their work and the interest of broadcasting organizations to seek the largest audience possible seem to go hand in hand. (ibid)

Similar to the freak show, which sought to involve its audience in the spectacle by 'humanizing' the freak, thus blurring the lines between human and 'other' to maximize appeal and profit, the medical documentary attempts to establish a connection between the patient and the viewer. In *Conjoined Twins: High Stakes Surgery*, the viewer is told that they are witnessing a shared journey and that the boys are only part of the story. Their unusual body may gather interest on its own, but that body, combined with heroic doctors, generous hospitals, and cutting edge medical technology in a filmic medium, becomes the spectacle.

The viewer learns that Aguirre was told during a routine sonogram at four and a half months that she was carrying conjoined twins. Images of her sonogram appear as proof for the viewer. This penetrative visualization of Aguirre's body singles out the 'problem' of the twins even before they are born and highlights a conundrum that medical technologies present for the mother: because "these medical disciplines isolate specific types of abnormality or deviancy, they construct new norms of healthy and responsible motherhood" (Sawicki 1999: 194). Aguirre describes the overwhelming fear she experienced when she was told about the twins but also explains that abortion was never an option for her. The narrator, Curry, states in a somewhat disapproving tone that it would have perhaps been easier to opt for the abortion, but Aguirre confirms her desires to have the boys regardless of their condition. For the first time in the documentary, the viewer feels somewhat ambiguously toward Aguirre: the implication is that she is partly to blame for the boys' present situation. In *The Transparent Body* (2005), van Dijck explores the clinical and emotional intersections of sonography, describing the difficulty that imaging technologies present for an expectant mother. According to her, these supposedly neutral images are anything but purely medical. In fact, they have become so wrapped up in "cumbersome nonmedical (emotional, cultural) connotations" that they present even greater difficulty for a parent (101). Furthermore, scans may diminish a woman's autonomy because she must rely more heavily on medical experts to interpret the

image according to their own beliefs and knowledge. Thus, it is not only the twins' body, but also the maternal body that is medicalized.

Arlene explains that abortion was never an option for her, so she could only look with hope toward the future, the 'moment when' the boys could be separated. Arlene elaborates on the daily difficulties of raising the boys. She is particularly disturbed by friends and neighbors who cry when they see the twins: "The first time they saw Carl and Clarence they usually cry [sic] so I told them that, you know I don't need that. Just stop it. If you want to cry, don't in front of my boys". Curry then explains what was implied earlier—that Arlene dreamed of separating the boys from the very beginning, despite having "seen stories about some cases and [knowing] that these surgeries were fraught with danger". In placing Curry's statement about Arlene's hope for separation just after Arlene's own comment about friends and relatives crying at the sight of the boys, the documentary temporarily opens up the possibility of viewing their conjoinment as a social problem, as well as medical one, yet the implications are not fully realized. When Arlene states emphatically that she does not want anyone's pity, she reveals that she is seeking medical intervention not just because of practicalities (mobility, daily functioning, etc), but also to correct a visually stigmatizing difference that would result in the boys being treated "as if they were invisible, nonexistent, or dead" (Coleman 1997: 226).

To increase the dramatic effect and heighten the anticipatory nature of the programme, statistics and newspaper clippings about conjoined twins alternate on the screen while Curry explains that until the 1980s the weaker of conjoined twins was usually sacrificed in the interest of the stronger one. The case of Ladan and Laleh Bijani and the story of two anonymous young Guatemalan twin girls,²⁸ who underwent a similar surgery, are briefly alluded to. In the first case, both died. In the second, one girl contracted a post-operative infection that has left her neurologically impaired. In using these particular examples, the documentary builds tension by providing not a single instance of a successful surgery, thereby reiterating the seemingly impossible nature of the surgery. When Curry asks

²⁸ While the names of these twin girls are not provided, they are likely Maria de Jesus and Maria Teresa Quiej-Alvarez (known as Josie and Teresita, respectively) who were separated in 2002 at Mattel Children's Hospital at the University of California Los Angeles Medical Center when they were a year old.

Aguierre why she is willing to take the risks that have been alluded to in the presentation of the failed surgeries, she responds, “I don't want that they [sic] blame me”, to which Curry replies, “You don't want them to say, 'Mom, why didn't you take care of me? Why didn't you separate us'”? Surgery is presented as imperative by imagining the boys' future resentment if they were not separated.

The boys' national and ethnic difference is alluded to when the image of a waving American flag dominates the end of the first segment. Not only are the twins brought to the United States because they cannot be helped adequately in their own country, but their body also proves to be unknown territory for the team of surgeons who will attempt the separation. Neville Hoad's analysis of the 'missionary impulse' in “Cosmetic Surgeons of the Social” (2004) is relevant here.²⁹ He explains that in the case of imperial endeavors, “[i]t was deemed that the natives needed to be saved from themselves. The call of the colonizable was heard as the call of the human being in the making” (200). Dreger echoes this argument in *One of Us* (2004), in her discussion of medical documentaries in general:

These stories become much more troublesome when they focus on children who are brought from developing countries to North America or Europe for high-tech normalization. [...] [S]uch films avoid disturbing the general public by cloaking themselves in the mythology of a quest narrative: the brave and heroic child undergoes great trials to achieve a noble destiny.” (126)

The Aguierre documentary uses sustained images of the American flag, which reinforces the idea of benevolent American doctors, who are doubly rescuing Carl and Clarence, first from a 'less-advanced' country, and second from a morphological condition that renders life unbearable. Dr. Goodrich explains how the team of surgeons ultimately decided to proceed with the 'expedition' into the unknown territory of the boys' body: “We just went around the room, said 'Can it be done, can it be done. Are there any of you out there that feel that this can't be done? Or are there issues?' We got done, the vote was 100%”. ‘Can it’ signifies that the only possibility worth considering is whether the doctors have the knowledge and ability to separate the boys, not whether it ‘should’ be done. Their final

²⁹ The word ‘mission’ in this context describes an occasion for a group to enter foreign territory to establish a connection or offer a service.

decision to proceed, which comes down to a vote, describes a pseudo-democratic process that excludes the opinion of the people most affected: Carl and Clarence and, by extension, their mother. In combination with the image of the waving American flag, the doctors' decision is an expression of power over a body or nation that is helpless in handling its own problems. Arlene must bring her boys to America for them to have any hope of achieving 'normalcy'. This image of colonization is reiterated by Curry's assessment of the situation: in agreeing to take the case, doctors would be stepping into "highly uncharted territory". This is supported by footage of the doctors staging the surgery; as the bodies rotate on the table designed especially to accommodate the twins, medical models of their skulls show the map of the surgical cut. Curry says, reminiscent of the emigrant experience, "The Aguirres had traveled across an ocean and a continent for more than 26 hours. But the dangerous journey they would take was only about to begin".

At the same time that the documentary posits the surgeons as saviours and missionaries, it simultaneously impels the viewer to identify with this impulse to rescue. According to Lauren Berlant, this elicits compassion and turns the viewers into 'moral actors', as

we [occupants of the United States] cultivate compassion for those lacking the foundations for belonging *where we live*, and where we live is less the United States of promise and progress or rights and resources than it is a community whose fundamental asset is humane recognition" (2004: 3; her emphasis).

Using this analysis to read the documentary, the implication is that it is only in the United States that the twins' humanity can be recognized, and it is only in the US that the surgical separation can be offered. Berlant points out that "compassion is a term denoting privilege: the sufferer is *over there*" (ibid: 4, her emphasis). Feeling compassion creates a hierarchical relation between the person who feels compassion and the sufferer. Following this, viewers of the documentary feel compassion, but it is this compassion that simultaneously distances them from the twins. Viewers may feel for them, but not with them.

The second segment focuses more on Dr. Goodrich and the surgery as a historical precedent. He explains that it is a landmark case and reiterates the low success rate of separating conjoined twins:

Curry: How many times have two normal healthy children emerged from this kind of surgery without any damage?

Goodrich: There are no cases of that situation.

Curry: It's never happened?

Goodrich: No.

Even though all of the high-tech scans indicate that the Aguirre twins have separately functioning systems, so that the separation should be possible, Dr. Goodrich admits that when it comes to conjoined twins, medicine and technology cannot account for everything:

So far, everything we had predicted has come true but we haven't done the final separation. [...] What we don't know and the question that we have not yet answered about children that are conjoined is the embryology of their joining is so unique that no matter what way you do it, you can't get around the problems associated with it.

On a narrative level, this emphasis on the possible complications and unknown risks of the boys' surgery increases suspense. In keeping with the medical model of disability, however, the dangers of surgery do not lead either doctors or journalists to question whether surgery itself is the only option for the twins.

Anticipation is maintained in the way the documentary is organized: the surgeries to separate the boys only begin in the second half of the program, but they are constantly alluded to in the first half, supporting the drive toward separation. In the third segment, three of the four surgeries are shown in detail along with the boys' continuing progress in both physical and occupational therapy. It is in this segment that the most detailed, invasive images of the boys are shown. By allowing viewers to see the medical 3-D models and images that help the doctors navigate the intricate physical connections between the boys, they are amongst the team of medical professionals who are literally inside of the boys' skulls as they operate. The camera changes quickly between images of the bustle of the surgical theatre and the boys lying on a distant table, to close-up shots from the surgeon's perspective. In these cases, it is as if the viewer becomes the surgeon. For a moment, the viewer observes the veins and connective tissues inside the boys' skulls just as Dr. Goodrich does. Then the camera changes to show Dr. Goodrich's hand clamping the sagittal sinus, the main sinus that drains blood from the brain. This succession of shots has the effect of facilitating identification with his authoritative role.

During each surgery, doctors and family members express optimism. Dr. Staffenberg describes his vision of the boys' future, post-separation: "Clarence has got a soccer ball; Carl's got a little football and it's a very happy thing". Aguirre's mother says from her home in the Philippines, "I wish that when they come home, the boys are walking so they can play with their cousins in the Philippines". Curry notes that the boys are becoming much more social and personable as their journey toward separation progresses, while their physical therapist, Mara Abrams, notes their "beautiful potential". All of this reinforces the element of hope for 'normalcy' that underscores this documentary. At the same time, these cues immediately precede images that show how the boys are in the present and point to the possible surgical damage doctors are trying to avoid. For instance, Dr. Goodrich studies holographic imaging (which Curry explains has never before been used in separation surgery), while Dr. Staffenberg reviews paths of incisions that he has mapped to minimize visible scarring. He remarks that the boys will be much better off in school with their friends if they have 'normal' hair patterns and if facial scarring is minimal. This is another indication of the effect of stigma on the lived body; normalization procedures are inextricably linked to the visual appearance and social status of patients rather than their physical health alone. Staffenberg is effectively trying to prevent one stigma from replacing the original one because he is cognizant of the fact that 'normalcy' is about blending—not bearing the scars of conjoinment. The complex ways in which the physical and the social intersect are thus alluded to, but again, they are not discussed openly in the documentary.

The last segment of the documentary centers on the final, most complicated surgery. While the other segments have proceeded without breaks, this one is interrupted by a commercial to maintain suspense until the very last cut. The segment begins with scenes of the boys' second birthday in the hospital, surrounded by the medical professionals, who have apparently become like family to Aguirre and her children. Dr. Goodrich mentions that he has no children of his own—and there has been no mention of a father figure in the boys' lives—so the narrative positions the Aguirre boys as his 'adopted' children. It is up to the American doctor to fill this void in their lives. All of the images are celebratory and positive, a continuation of the optimism that pervaded the previous segment.

The boys have reached another milestone and are still moving progressively toward their 'normal' future. Curry momentarily severs the joy of the scene by warning viewers, just before the commercial, to "remember, in surgeries like this, death and brain damage are commonplace", thereby maintaining narrative suspense, but hope is sustained when Dr. Goodrich says that he is optimistic, having looked at every anatomical and vascular angle of these two boys.

During surgery, familiar images remind viewers of the passing time. There is the ticking clock inside of the operating room, footage of Arlene and her mother (newly arrived from the Philippines) waiting for information, even a shot of Arlene's wristwatch, all to provide visual cues marking the anticipation of the 'moment when' doctors will emerge to deliver news. Curry explains that Dr. Goodrich is "armed with the latest technology", a reference to the 'battle' that he is waging against the boys' abnormal body. In addition to close-ups of the surgical site that are shown both on a monitor in the operating room (that doctors are using) and through a film camera, there are also close-up shots of the heart and blood pressure monitors. Viewers hear heart monitor beeps, suction, and buzzing from drill-like tools. Surgical gauze dampened with blood, doctors in protective masks, and several tables of operating instruments and supplies are images that give the sense of immediacy and audience participation. Goodrich is moving "micrometer by micrometer" toward the final moment; he is "gaining momentum", according to Dr. Staffenberg.

During the final hours of the surgery, narrative tension is sustained again when the surgical team discovers something that all of its planning and advanced technology never revealed: Carl and Clarence do in fact share a small part of the brain. While the viewer has been assured all along that the doctors would stop if they found anything unusual or unexpected, they are now, according to Curry, at the "point of no return". The narrative has reached its climax, and in a voiceover, she pronounces: "It all comes down to this moment. This final cut will make what was once a fused brain into two. It is the kind of dangerous incision that doctors had worked to avoid". After a moment of hesitation, Dr. Goodrich announces to a clapping and cheering team, "Well folks, we are separated. Congratulations". He chooses 'we', rather than 'they', to re-emphasize the shared journey. Ironically, however, given that the surgery was meant to allow the boys to live and be

recognized as two distinct subjects, their subjectivity is now subsumed under the more general first person plural. At the same time, the inclusion of the twins in this shared 'we' also indicates that they are now free from their 'other' body and therefore granted the same status as other 'normal' subjects around them. When Dr. Staffenberg goes to the waiting room, his comment to Arlene once again reinforces the belief that it is the closed and singular body alone that permits full autonomy, agency, and subjectivity: "You have two little boys, two little boys. They're doing great. They're doing great". In her final comments at the end of the documentary, Curry refers to the boys' separation as a moment of rebirth. She says, "For Arlene Aguirre, a woman of faith who was looking for a miracle, now she has two of them". The surgery is perceived as successful, because the boys now have two bodies, distinguished by clear borders, allowing them to have what Curry calls a "real future".

However, in the limited follow-up of the twins' post-surgical progress at the close of the documentary, it appears that the 'moment when' they can live a normal life is delayed. Years after the surgery, they are still in transition; their narrative of becoming did not end with the surgical separation, which marks the conclusion of the documentary. As Goffman states, even in cases where the stigmatized person makes an attempt to fix the problem, "what often results is not the acquisition of fully normal status, but a transformation of self from someone with a particular blemish into someone with a record of having corrected a particular blemish" (1986: 9). For conjoined twins, the physical traces left by surgery (scarring, delayed development, other physical disabilities, etc.) and the invisible psychosocial marks act as reminders of the previous state of conjoinment. Carl and Clarence, who continue to undergo therapy, wear helmets to protect their skulls, and face the possibility of reconstructive surgery. For them, there exists the continuing need to narrate their lives and their bodies around the trace of their conjoinment; the boys are always therefore the representation of a work 'in progress'; this is the image with which viewers are left. When showing the twins in their present 'lack of normalcy', the documentary concedes that further medical interventions are needed to 'fix' them, once again upholding—rather than destabilizing—the medical model of disability. Even though the twins are, in terms of their bodies, two separate boys, they still are not the 'normal'

children that everyone envisioned throughout the documentary. They are still in need of further medical intervention and rehabilitation.

Fictional Surgical Separation: *Nip/Tuck*: “Rose and Raven Rosenberg”

In contrast to the documentaries discussed in this chapter so far, the award-winning American drama *Nip/Tuck*, which aired for seven seasons beginning in 2003, playfully and subversively engages with generic characteristics of medical documentaries. In episode 22, “Rose and Raven Rosenberg”, which aired during the show’s second season, McNamara and Troy are called upon to lend their expertise as part of an assembly of surgeons who will be separating craniopagus conjoined twins, played by real-life conjoined twins Reba and Lori Schappell. By having the Schappell sisters play the conjoined twins in the episode, the factual and the fictional are blurred. As has been argued, all documentaries are hybrid in that they combine fact and fiction, but this generic instability is not usually openly acknowledged in medical documentaries. *Nip/Tuck*, on the other hand, offers a more self-reflexive and critical commentary on the medical treatment of different bodies. In the episode, the Rosenberg twins reluctantly undergo separation surgery with tragic results whereas the Schappells have rejected the option of separation. Through the discrepancy between the actors’ lives and the characters’ fate in the show, *Nip/Tuck* articulates a powerful challenge to the medical model of disability and the contentious issue of separation surgery.

Nip/Tuck follows the fictional professional and personal lives of best friends and plastic surgeons, Sean McNamara and Christian Troy. Each episode narrates one or more cosmetic surgeries undertaken by the two surgeons, who ask their clients in pre-surgical consultations to “tell [them] what [clients] don’t like about [themselves].” At the point in the series when the Rosenbergs enter their practice, McNamara and Troy are facing personal problems that are interfering with their ability and desire to continue working together as business partners. Sean has recently discovered that Christian had a brief affair with his wife, Julia, just before they were married, which resulted in her becoming pregnant with Matt, the child that Sean has been raising for 17 years as his own. Sean has asked Julia to leave the family home, and he has told Christian that he can

no longer see a future for their shared business; his intention is to split the practice and begin again on his own. This sets up their encounter with the conjoined Rosenberg twins—subsumed as a narrative metaphor for the McNamara/Troy partnership, which is also on the verge of separation.

Throughout the episode, McNamara and Troy are likened to conjoined twins. Every aspect of their lives is intertwined, and it is the delicate ‘operation’ of untangling their many bonds that provides the undercurrent of this show. This is obvious in the references to their relationship, which is described by Christian as “symbiotic”. They are likened to brothers, partners, the heads of a family (their practice); they even share a son who is referred to by Sean at the end of the episode as “the best thing [their] partnership ever produced”. Reluctant to separate, Christian suggests that they seek help from the best couple therapist in Miami, and when they discuss the splitting of their shared assets, he refers to it as getting “custody”. All of this suggests a relationship that is simultaneously familial, marital, professional, and homosocial.

Their metaphorical conjoinment is further highlighted by the sub-plot of Rose and Raven, who are seeking separation for one reason: Rose has cancer, and because Raven is not strong enough to handle chemotherapy, they must separate if either is to have any chance of surviving in the long term. While Sean is seeking a separation from his ‘conjoined twin’ because they cannot get along, Rose and Raven are only seeking separation because the alternative is death. In contrast to the medical documentaries discussed above, separation is decidedly not presented as an inevitable step towards a fulfilled life. Rather, it is viewed as the last option the Rosenbergs have to survive, as viewers are told that “lives are at stake” in this high profile, pro bono surgery. At a pre-surgical meeting to which the medical team has been called, their mother explains that she wants them to get to know the girls as she knows them, “to see the things about them that CT scans and MRI’s do not show”. Here, the medical model of disability, which views physical difference in exclusively medical terms, is undermined; instead, the twins are presented as individuals that cannot successfully and exhaustively be understood using medical technologies alone. One doctor asks how the sisters handle their personal needs, while another asks what happens when one is tired and the other is not. The twins’ responses point to the ‘normality’ of their lives,

and they render absurd these questions: When one twin is tired, she sleeps while the other reads; and while one twin prefers to shower in the morning, the other prefers a bath in the evening. They are then asked “What about intimate relations? Do you have boyfriends?” Rose says that she had a boyfriend at one time, but had to break up with him because Raven “couldn’t stand him, but Raven is my best friend, so I had to put her feelings first.” The show suggests that it is society’s response to conjoinment rather than the actual physical facts associated with this condition that render it pathological.

When Christian introduces himself as one of the plastic surgeons, the girls turn the questioning ritual around, asking him how they will look post-surgery. Sean rises and asks, “How do you want to look?” Rather than associate surgery with a newfound positive sense of distinct subjectivity, as is common in medical documentaries, the Rosenbergs want to look as much alike as possible because in looking alike, they can still claim the detached sister as an extension of themselves. This points to the overall contentment that they have with their physical conjoinment. Even though they will no longer be joined physically, they want to preserve their attachment in another way. This surprises Sean, who is seeking a definitive separation from his ‘conjoined twin’, Christian, and he follows up by asking, “Have you thought about what it’s going to be like to be separated? Any fantasies about being alone for the first time?” When they both respond “no”, he asks whether they have dreamed about the “amazing sense of freedom and release” they will experience post-separation. This is the first question that deals with the ‘feelings’ associated with separation. Rose explains that she once had a dream they were separated, and she was scared, so she reached out to Raven, but Raven was not there. Then she adds, “To you, being together looks hard, but it’s all we know”. Reba and Lori Schappell have made similar statements about their real-life situation, and as Alice Dreger has pointed out about conjoined twins in general, “conjoinment becomes so essential to [twins]—to their sense of who they are—that they cannot readily conceive of living in a different mode” (2004: 47). Because the Rosenberg’s story is juxtaposed with Christian and Sean’s struggle to stay together, the show indicates that the longing for separation is not necessarily one felt by conjoined twins themselves; rather it is projected onto them by others, in this case, the surgeons who are going to treat them.

Many of the same visual and auditory cues appear at the beginning of the sisters' fictional surgery, including the drawn dotted lines marking the path of the surgical cut, the clock, the beep and murmur of machines, and the synchronization of the surgeons (each team of two is wearing a different colored gown). The show even depicts a surgical table that turns, much like the one that was designed to move Carl and Clarence Aguirre with minimal jarring of the surgical site. As they are about to separate, the announcement is made: "On the count of three", then the tables split for the first time and the team designated to each girl goes to work to repair their individual bodies. To mirror the split of the twins, one surgeon from each pair goes to each girl; it is Christian who works on Raven, while Sean handles Rose's reconstruction. Shortly after the split, Raven's sagittal sinus bursts, which results in her death. This is the same sinus that went undetected in the case of the Brodie twins, resulting in the death of one sibling. Furthermore, it was the clamping of the sagittal sinus that provided the 'climactic moment' in the Aguirre documentary. Almost immediately, Rose begins to deteriorate, but none of the doctors can find any physical cause. Christian hypothesizes that "Maybe she knows her sister's gone, and she's giving up". This situation is reminiscent of the real-life case of Katie and Eilish Holton, Irish conjoined twins who were born in 1988 and separated in 1992. Katie died of complications resulting from a weak heart. According to Kathy Donaghy in "Life After Katie" (2000),

[O]n an early spring day in 1992, the operation was carried out. It took the best part of 24 hours and was pronounced a success. But four days later, for no apparent reason, the monitors attached to Eilish's heavily sedated body began to behave erratically. Doctors later put it down to the fact that she had reacted in sympathy with her little sister who was dying beside her. She had suffered a coronary arrest.

Sean refuses to accept that Rose is reliant on Raven in ways that medicine cannot explain. Working to restore her vital signs, he says, "She can survive on her own. She can survive. She can survive on her own." Rose's heart rate recovers, and the surgical segment of the show concludes. In Rose's survival, Sean has seen that he too can survive without Christian; he does not need to be part of any team. It will be Christian, like the weaker twin, who will ultimately succumb to the separation. Rose's survival without her sister is not presented as the result of her own desire or will; indeed, Christian's remark implies that she might not want to live without

her sister. Thus, again, post-separation life and the distinct subjectivity it is supposed to bring are shown to be desirable primarily for others, like Sean, who projects his own desire for independence onto his patient.

In a scene typical of this show, Sean goes to a bar following the surgery, meets a sex worker whom he later 'names' Julia, after his wife, and then brings her back to the hospital dormitory room that he shares with Christian. Both men have sex with her on a makeshift bed that they have created from two smaller beds and her face morphs into that of Christian's former lover and Sean's wife, Julia. Initially, each man takes his turn while the other looks on, and then they engage in a 'threesome'. Once she has gone, they split the beds again. This scene functions on many levels. First, the splitting of the beds is a symbolic nod to the earlier surgery, while their joining back together foreshadows the end of the episode. Further, there is no question that the scene as a whole insinuates the sexual dynamics of conjoined twins, which is a recurring topic of discussion and fascination. When each individual man is having sex with 'Julia', the camera captures their full bodies, thus emphasizing their singularity. Yet when they are sharing 'Julia', the shots are close-ups only. This, along with the constant fading in and out of the trio, emphasizes their entanglement.

The following day when Christian returns to check on Rose, her mother explains that she was reaching out all night long, grasping at something, but as soon as she told her that Raven was in Heaven, her fingers stopped moving. She says to Sean: "If she gets better, and we can take her off of this thing, she's isn't going to have much of a life, is she, other than to be studied? Other than to have those damn tabloids sneak in and try to take a picture?" Sean acknowledges that "she'll probably never have the same quality of life on her own", pointing to the residual effects of separation surgery. The show thus subverts the 'moment when', which is elsewhere presented as the solution to conjoinment. Rather, it becomes apparent that Rose is neither physically nor emotionally complete without Raven and that surgery has negatively affected her overall wellbeing. The twins' mother explains that the sisters had a living will, which outlines their explicit wishes, but that she did not tell anyone because she did not want to be alone. This seems to challenge the singleton's belief that 'alone' is preferable; conjoined twins are never alone, and she seems to desire what they had. She understands that she

must take Rose off of life support, but before doing so, she makes one request: “After I do it, will you put them back together, the way they were, so they can be together forever, as God wanted them to be?” Sean nods, and this opens the final scene of the show. As Sean and Christian are working together to restore the twins to their conjoined state, Sean says: “I am a better doctor because of you, Christian. A better doctor with you”. In contrast to medical documentaries, whose generic characteristics are playfully employed by the show, conjoinment is here idealized, serving as a metaphor of togetherness, friendship and mutual dependence.

To further reinforce, the two doctors’ ‘conjoinment’, Sean refers to Matt, their ‘mutual’ son, as their best work, and decides that Matt establishes “a connection [he] can’t let die”; he is the site of their conjoinment, the remnant that cannot be erased through any separation. With that, Sean makes the final cut of the show, snipping the leftover bit of the stitch that is now securing all of them (Rose and Raven and Sean and Christian) together again. The cut in this context re-establishes their conjoinment rather than solidify their separation. The twins, in addition to the McNamara/Troy partnership, are rendered whole again. As the lawyer handling Christian and Sean’s separation stated at the beginning of the show, “Apart [they] are nowhere near as strong as [they] are together”. Similarly, when viewers see Rose and Raven pre-surgery, they see women with a physical difference, who go about their lives as other, ‘normal’ people would. Post-surgery, they are incomplete, and through their disconnection, Christian and Sean learn to see the benefits of their own partnership.

The fictionalized separation of Rose and Raven Rosenberg emphasizes what medical documentaries tend to neglect: a recognition of individuality as more than biology and an awareness that cutting a conjoined body into two distinct bodies does not automatically create two healthy and fulfilled subjects. Rather, the show indicates that establishing the ‘self’ is about negotiating borders with an ‘other’—be that ‘other’ a twin, a friend or partner, or society in general. This complex negotiation of self and other in social rather than medical contexts is one that I turn to in the following chapter, which examines various alternative forms of disability narratives. How are conjoined twins constructed when their social environment, rather than their body, becomes the focus?

Chapter 3

Social Disability in Contemporary Documentary Film

Over the last two decades, a growing number of disability documentaries have tended to position disability principally as a social construct rather than a physical problem demanding a medical solution. In contrast to the medical documentaries discussed in the previous chapter, they do not focus on ‘fixing’ the impairment itself, but rather emphasize changing social perceptions and prejudices. In doing so, these documentaries are “moving away from adjustment and towards empowerment” (Oliver 1996: 32). To this end, they can be said to adhere to a ‘social model’ of disability, which Tom Shakespeare calls a “redefinition” (2006: 29),

shift[ing] attention from individuals and their physical or mental deficits to the ways in which society includes or excludes them. The social model is social constructionist [...], rather than reductionist or biologically determinist. Rather than essentialising disability, it signals that the experience of disabled people is dependent on social context, and differs in different cultures and at different times. Rather than disability being inescapable, it becomes a product of social arrangements, and can thus be reduced, or possibly even eliminated. (ibid)

Shakespeare, and others (Siebers 2008, Barnes and Mercer 2010), have discussed the origins, as well as the benefits of this model, pointing in particular to the ways that its emphasis on “the built environment presents a common cause around which [people with disabilities] can organize politically” (Siebers 2008: 73). It also served to empower disabled people who were “able to understand that it was society which was at fault, not themselves. They didn’t need to change: society needed to change” (Shakespeare 2006: 30). As a result, the shift from a medical model to a social model of disability produced a social and political movement that was similar to those experienced by other historically oppressed groups. Shakespeare also observes the impact of the social model on academia:

Whereas the medical sociology of disability had traditionally investigated issues such as individual adjustment to impairment and explored the consequences of impairment for identity, the social model [...] enabled the focus to be widened from studying individuals to exposing broader social and cultural processes. (ibid)

In this sense, the social model of disability has had a significant impact not only on real world policy, but also on academic debate.

The disability documentaries discussed in this chapter draw on the social model of disability to highlight the ways in which society constructs disability through generalizing assumptions that reflect prejudice and result in discrimination. Through their examination of this process, these films seek to expose and counter “assumptions [that are] made about people born with unusual anatomies” (Dreger 2004: 6), which then “become self-fulfilling prophecies” (ibid: 16). Such assumptions are based on generalizations, which feed into prejudice, as Gordon Allport has argued in his seminal text, *The Nature of Prejudice* (1979). Allport defines prejudice as

an antipathy based upon a faulty and inflexible generalization. It may be felt or expressed. It may be directed toward a group as a whole, or toward an individual because he is a member of that group. The net effect of prejudice, thus defined, is to place the object of prejudice at some disadvantage not merited by his own misconduct. (9)

If, as Allport concludes, prejudice arises from a “process of categorization” (ibid: 20) upon which “orderly living depends” (ibid), then it is expected that humans will make generalizations about groups of people who are outside of the dominant majority—to separate them psychically and sometimes physically. As I argued in chapter one, this process of separation has been a central characteristic of the historical treatment of ‘monsters’, ‘freaks’, and now ‘disabled people’ because prejudice and discrimination “are simultaneously present and form parts of a single story” (ibid: 514).

Disability documentaries that adopt the social model of disability seek to uncover these processes; in their representation of disability, they have the potential to upset and possibly overturn prejudices because “visual language [not only] reflect[s] a truth about the world which is already there [...] [but might also] produce meaning about the world through representing it” (Hall 1997: 7). Disability documentary aims to represent disability in such a way that a change in public perception becomes possible. This change consists of changing the idea that “a person with a disease or disability [...] has a ‘broken’ body needing fixing, [into a perception of that person] as someone whose body differs from the statistical average, but as someone whose body is a variation on the human experience”

(Asch 1995 : 152). These documentaries—and the documentaries that I examine in this chapter—are examples of what Thomas Couser, in *Signifying Bodies: Disability in Contemporary Life Writing* (2009), refers to as ‘some body’³⁰ memoirs, which are “[...] often about what it’s like to have or to *be*, to live in or *as*, a particular body—indeed, a body that is usually odd or anomalous” (2; his emphasis). Because they focus more on society, these new disability films, according to Snyder and Mitchell, in *Cultural Locations of Disability* (2006), encourage their audience “to respond with revulsion at the debasing mindset that dominates the characters’ interactions with an able-bodied world. [...] [N]ew disability documentary cinema designates degrading social contexts as that which need to be rehabilitated” (173). These disability documentaries have enjoyed tremendous success over the past two decades.

When Billy Broke His Head (1994), an award-winning documentary featuring Billy Golfus, a radio journalist who has dealt with a brain injury since being struck by a car in 1984, is a candid depiction of the daily political and social injustices that have provoked a sustained disability rights movement in the United States. The film acknowledges disability as a medical reality, but it simultaneously positions it as an entanglement of factors located outside of the body—factors that disenfranchise disabled people. The 2000 Academy Award-winning documentary by filmmakers William Whiteford and Susan Hannah Hadary, *King Gimp* (1999), follows renowned painter Dan Keplinger for thirteen years of his life as he struggles to overcome the limitations caused by cerebral palsy and gain acceptance in mainstream society. Experiencing many common milestones despite his limitations—senior prom, graduation, moving out of his mother’s home, and his first career success—Keplinger learns how to adapt his environment to suit his individual needs. Using a head stick, for example, allows him to control the brush to paint. *My Flesh and Blood* (2003) showcases a year in the lives of Susan Tom and her 11 adopted, special-needs children who have disabilities/illnesses ranging from cystic fibrosis and epidermolysis bullosis to

³⁰ This expression is Couser’s reworking of Lorraine Adams’ term “nobody memoir”, from her article “Almost Famous: The Rise of the ‘Nobody’ Memoir” in the *Washington Monthly*. The ‘nobody memoir’, according to Adams, is about someone who is relatively unknown before the publication of the work. Couser notes that because two out of three of Adams’ categories of ‘nobody memoirs’ are “constituted by disability” (2009: 2), ‘some body’ is a more accurate description. ‘Somebody memoirs’ “have pre-existing audiences created by the eminence of their authors” (ibid: 1).

being born without legs. Directed by Jonathan Karsh, the documentary details some of the social and medical challenges the children face, as well as one of their deaths. It ends with Susan Tom's assessment of the year: "It's been an up and down year, but we've had many up and down years. There are always happy times and sad times and stressful times, but all in all, it's your life, and you live it" (2003). Finally, *Emmanuel's Gift* (2005), directed by Lisa Lax and Nancy Stern, chronicles the life of a young Ghanaian man, Emmanuel Ofori Yeboah, who was born with a severely deformed right leg. Rather than become one of Ghana's two million forgotten disabled people, Yeboah embarks on a mission to change his country's limited view of disability by bicycling 600 kilometers across Ghana. His mission is to break down the barriers that Ghana continues to reinforce against its disabled population, but it is also a testimony to the social injustices that disabled people face all over the world.

Many contemporary filmic representations of conjoined twins have moved beyond the traditional 'rehabilitation through separation' story, allowing viewers to see "non-normative morphology, not as a failure of form (inviting therapeutic modification), but as an-other way of being" (Shildrik, 1999: 79). However, as I will show, there are advantages and limitations in relocating the locus of disability from the twins' shared body to society's reception/perception of that body. Representing disability as socially constructed, these documentaries at times turn the twins into victims, not of medical authorities, but of a society that fails to initiate them fully into 'normal' life. On the other hand, they are progressive in that they begin to open up an understanding of conjoined living (and disability as a whole) as a complex experience of personal impairment and social construction. To be clear, my examination of representations of conjoined twins in recent documentaries is not meant to be categorical; characterizing any representation as either wholly 'positive' or 'negative' would be reductive. Rather, by examining these representations, I hope to identify and better understand the myriad ways in which representations of conjoined twins—and marginal groups as a whole—are constructed.

In the previous chapter, I sought to identify how medical documentaries place conjoined twins in a position that is at once central and peripheral. While these documentaries are *about* particular conjoined twins in the sense that they

are ‘concerned with’ their separation, they are also *about* them in the adverbial sense. In other words, in placing the twins always at or near the periphery, there is equal (or greater) attention paid to what is going on *about*—‘around’ or ‘near’—them. Doctors, family members and narrators construct the twins as always ‘in progress’, moving toward a normative future in which they are free from their physical difference, one in which they achieve invisibility—a desired attribute—within society. In the medical documentary, this approach permits the viewer to share the medical gaze, and actively partake in the transformation of the twins’ abnormal body.

This same tactic of using the central and peripheral positions interchangeably works to a much different end in documentaries that do not rely on separation to drive the narrative. In these films, the audience is led to question whether it is the twins or society that is the ‘other’ on display. As the spectacle becomes the spectator, and the spectator becomes the spectacle, the “norms that marginalize and stigmatize disabled people—the norms that make them vulnerable subjects” are challenged, rather than reinforced (Couser 2009: 30). Overall, this chapter argues that such documentaries, which present predominantly a social model of disability, succeed in exposing many of the stereotypes inherent in medical documentaries and offer at least a greater compromise between what are often regarded as opposing models of disability. At the same time, however, these documentaries also inscribe other sets of values and norms and therefore do not offer a radical deconstruction of social understandings of ‘normalcy’ and disability.

First, I extend Couser’s examination of *Face to Face: The Schappell Twins* (1999) by reconsidering its successes and addressing, as well, its limitations. Afterwards, I turn to an examination of two documentaries on Abigail and Brittany Hensel: *Joined for Life* (2002) and *Joined for Life: Abby and Brittany Turn 16* (2006) to analyze the differences between a documentary that presents “a filmed portrait of [two adult] twins at a certain stage of their lives” (the Schappells) and two documentaries that approach younger conjoined twins (the Hensels) in a more traditional way: as a modified biopic that is still in progress (Couser 2009: 57).

“Face to Face: The Schappells”

Directed by Ellen Weisbrod, *Face to Face* follows the oldest-known living female craniopagus twins, Lori and Reba Schappell, as they go about their daily lives in Reading, Pennsylvania and as they move beyond the confines of Reading, for instance, visiting major tourist areas such as New York City. In his discussion of the film, Couser explains that his goal is to “[explore] how and whether nonprejudicial representation is possible when the body in question is conventionally the passive recipient of curious, appraising, or clinical gazes, at best; at worst, a stimulus to pity and revulsion” (2009: 50). He ultimately concludes that it is indeed possible; the film’s overall success has mainly to do with its ability to get beyond “the standard medical documentary approach” (ibid: 56). Yet this success is also its failure to an extent. Weisbrod produces a film that challenges the view of visually different bodies as medical problems, but as I illustrate later in this chapter, there is a risk in shifting this view to another extreme.

The film begins with an off-screen interviewer speaking to random people on the streets of New York City and showing them images and/or video of Lori and Reba on a portable player. The respondents react with a mix of confusion and shock: “Is that real?”; “That’s messed up.”; and “Thank God I had a kid and I didn’t have that.” are representative of the replies. The film then shifts to footage of Lori and Reba doing many of the daily tasks that the respondents likely do in their own lives. What is noticeable in the overall framework of the narrative is the evolution of their attitudes; as they become more aware of Lori and Reba—more accustomed to them—they begin to rethink their initial impressions. Toward the middle of the documentary, there is a slight shift in the sentiments of those same viewers, who are shown regarding the twins with a greater degree of understanding. One states: “These two ladies probably are better at a lot of things than we are because they’re used to a certain way, and they can get around and they know how to function in a certain way, and they probably don’t even think of it as a handicap because that’s all they know.” Another says, “They seem like it’s ok. They’re handling it fine. Like it doesn’t even bother them.” Finally, at the end of

the film, these interviewees have been moved toward “recognizing a ‘newness’ that can be transformative” (Garland-Thomson 2009: 188). Most respond positively to Lori and Reba, and those who have not made those adjustments in their opinions have become the outsiders. When an interviewee states: “I can’t imagine why you would show me a picture of such a thing” or “I don’t think you should put that on camera”, the audience has already adapted their own perceptions and adjusted to the girls. They have become “initiated viewers” that can now critically respond to prejudicial statements (ibid: 114). Rosemarie Garland-Thomson, in a brief examination of *Face to Face*’s starrer/staree dynamic in *Ways of Staring* (2006), praises the film’s ability

to make singleton viewers accustomed to and charmed by the twins so that, when the many interviewed starrers reveal their own prejudices and lack of imagination in their comments about the twins, initiated viewers find themselves smirking at such naivete and bias because [...] they have come to find Reba and Lori unexceptionable and indeed lovable. (ibid)

Couser suggests further that the film produces “empathetic watching” (2009: 55) because it does not “[place] the viewer in the position of the distanced and objectifying viewer” but encourages them to experience the world through their perspective (ibid: 54-5).

In this sense, the documentary is equally about society and its reactions to Lori and Reba. To present this dual point of view—to turn viewers into ‘initiated viewers’—*Face to Face* employs multiple cameras and crosscutting to “bring Lori and Reba face to face with the audience almost simultaneously” (Couser, 2009: 63). Because it focuses on their individual faces as they speak, the viewer comes to see them not just as conjoined twins, but also as two distinct individuals. In addition, Couser elaborates upon the usefulness of allowing the viewer to see over the twins’ shoulders when they are out in public spaces. This aligns the audience with the twins rather than with onlookers, permitting them to “see through [their] eyes what [they] see” (ibid: 61). The film develops a multi-layered viewing that fosters a double-alignment with Lori and Reba. Not only do viewers see what the twins see, but they are also granted access to the wider, more inclusive view of the documentary camera. As viewers are watching the narrative unfold, they are not just seeing the twins or seeing over their shoulders; they are also seeing spectators at the periphery of Lori and Reba’s vision. The result is that the

spectators within the film become the spectacles for the documentary viewers because the audience is, as I stated earlier, already aligned with the Schappells; it is therefore implicated in reversing the spectator/spectacle dynamic. Rather than conclude that Lori and Reba are 'abnormal', viewers are likely to see onlookers' negative reactions as ill-informed.

In addition to what the documentary camera records from a distance, the Schappells also use a handheld video camera to capture the public's reactions to them. Rather than being the passive object of documentary attention, they literally reverse this viewpoint when they record those who openly stare at them. Thus, they reinforce their agency by once again transforming the spectator/spectacle dynamic. Placing themselves at the periphery of their own documentary—as the recorders—Lori and Reba become simultaneously central and peripheral. At one point in the film, the women are having lunch in New York City when two women dressed in saris stop to stare at them. It is a type of "separated staring" (2009: 114) that Garland-Thompson refers to as "baroque staring" (ibid: 50), staring that "blatantly announces the states of being wonderstruck and confounded. It is gaping-mouthed, unapologetic staring" (ibid). When Reba discovers them, she tells Lori that there are "two weird people" staring at them. Lori confronts the women, breaking the awkward encounter. "Excuse me, [she says;] we're eating". If, as Garland-Thomson asserts, this type of staring "entangles viewer and viewed in an urgent exchange that redefines both", then it is Lori who controls this exchange by asserting herself without apology. She reclaims their subject positions by focusing attention onto the starers. While the camera has often been used historically as a tool for constructing the 'other', for instance in photographs of freaks or medical documentaries discussed in previous chapters, it functions here as a deconstructive tool that challenges notions of 'normalcy' and deviance.

Another important characteristic of this documentary is its insistence on Lori and Reba's voices; there is no narrator, and both girls directly (and frequently) address their audience. The lack of a single 'authoritative' and disembodied narrator further reinforces Lori and Reba's individual subject positions. Almost immediately, they explain that they want to be called by their individual names, not "you two". Thus they assert their individuality in their own voices, mentioning that other non-joined twins are seen as individuals and that as

conjoined twins they are no different. Both sisters recognize their connection to the viewers they so often address. Lori in particular insists on difference, rather than normality, as an inclusive category; she challenges directly the assumption that there is something about her particular disability that makes it more or less tolerable—or ‘stareworthy’—than any other. According to her, most people have some type of disability:

Everyone has got something about them that’s different. Even a person wearing contacts. Something as little as wearing contacts to me is handicapped because they don’t have their [...] quote ‘normal’ vision. So what are you going to do—make sure that they have a table in the restaurant just for people who wear contacts so that they don’t associate with all those others who don’t have contacts? Why should I not sit with a person who doesn’t have somebody attached to them? Why should I only sit in a little place far away from the rest of the world? (sic)

Lori reinforces a connection with the viewer by asserting their ‘normalcy’ through their difference.

In her appraisal of disability rights activist Harriet McBryde Johnson’s use of the media and public appearances to teach people how to look at her, Garland-Thompson says

She gets them accustomed to looking at her by making herself more familiar than strange, by bringing her life story closer to their own. By getting them to see her as unremarkable in her distinctiveness, she makes it possible to identify with her own aliveness, which as she tells it, seems pretty much like theirs (2009: 192).

The Schappell documentary functions similarly. By immediately addressing the concerns/questions/ignorance of starers, it encourages viewers to evaluate and reconsider their own assumptions about what it means to be ‘normal’ or able-bodied. When, for instance, an off-camera interviewer asks what each twin would write in a personal ad, Reba says, “Don’t want to date. Thank you very much. Stay away.” Lori’s, on the other hand, would say,

I’m, uh, 5’4, brown hair, hazel eyes. I guess...well I can’t say ok looking. I’m average looking. Um...outgoing, willing to try anything new, um, enjoy having fun, movies, stuff like that, trips, quiet evenings at home. I don’t know. I guess that’s how I would put it (sic).

Lori mentions nothing about being a conjoined twin, which may indicate that she does not consider this a feature that makes her unattractive to a potential partner. Lori’s sense of her own physical attractiveness is based on the same physical

markers that any 'normal' person might use: height, hair color, eye color, etc. When the film cuts back to passersby who are asked to comment about aspects of their own physical appearance that they are self-conscious about—"features that cause them social stress"—it once again creates a link between Lori and Reba and viewers (Dreger 2004: 132). Not surprisingly, people express dissatisfaction with a variety of their physical characteristics. They share the same anxieties as Lori and Reba, and like them, "none of them say they have plans to alter those features" (ibid).

Similarly, when people express concern with the girls' lack of privacy, the film immediately addresses it by, ironically, bringing viewers into the intimate space of their apartment. There they are seen going about their daily business of being 'normal'. They lie in bed, brush their teeth, make breakfast, maintain separate bedrooms, do laundry, etc. While they obviously have a different understanding of public and private space than a singleton, the girls have learned to function as private beings. They can still, according to Lori and Reba, say "leave me alone" to each other; they can "block out" what they want to, whenever they want to. While they do not perhaps have the kind or degree of free will that allows them to move away physically, they have developed a coping strategy that works for them. According to Dreger, conjoined twins use this strategy even when dealing with physical intimacy: "Of course, the other twin is right there, but people who are conjoined [...] consistently report that during sexual intimacy their siblings remain quiet and mentally distant" (ibid: 49).

Face to Face "documents the clear disadvantage of the poor, tiresome singletons in staring encounters" and positions Lori and Reba as effective handlers of their difference, but even when Lori and Reba cannot hear the remarks that a passerby makes, the documentary acts on their behalf, directly addressing what viewers, at this point, have likely come to see as ignorance on the part of people who encounter them (Garland-Thomson 2009: 114). For example, immediately after a woman expresses disbelief that Lori and Reba are worthy subjects for a documentary because she should not have to "see that", the camera cuts to an extended session of them in the photography studio where they are having close-up portraits taken by a well-known New York photographer. In doing this, the documentary challenges the woman's ignorance by granting Lori and Reba even

greater visibility. This is a defiant response to those who would prefer to keep them hidden from society because they are visibly different. The documentary therefore echoes Lori and Reba's well-established opinion that they should not be denied a voice or a presence in society. According to Lori, she and Reba will not apologize for living their lives; they will not hide to accommodate anyone:

We're not going to sit at home just for you guys to go out and do your stuff, to make you happy. We're going to go out and live our lives, and if we run into you and you don't like us, that's your problem. I mean, I'm not trying to be nasty to you all out there but it is your problem.

Lori's view of her difference as a social rather than an individual problem illustrates the oppositional relationship between disability and impairment articulated in *The Fundamental Principles of Disability* (UPIAS 1976):

Thus we define impairment as lacking part or all of a limb, or having a defective limb, organ or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. Physical disability is therefore a particular form of social oppression. (14)

In other words, disability "is a social creation. Disability is what makes impairment a problem. For social modellists (sic), social barriers and social oppression constitute disability, and this is the area where research, analysis, campaigning, and change must occur" (Shakespeare 2006: 34). Visually representing the movements and experiences of a single, disabled body in a specific social and cultural context, *Face to Face* exposes the social limitations of 'different' bodies. As a result, it suggests a positive shift in the representation and treatment of 'other' bodies, not by presenting positive images, so to speak, but by opening up the process of representation.

Limitations of *Face to Face*

While I agree with Couser's conclusion that this documentary "is the antithesis of the medical documentary", the film's presentation of disability as socially constructed also needs to be problematized (2009: 54). Michael Oliver argues that a medical approach to disability "produces definitions of disability which are

partial and limited and which fail to take into account wider aspects of disability” (1990: 5), yet his assumption could be applied equally to a completely social model, which also reinforces binaries and limits the experience of a disabled person. Accordingly, a documentary that represents Lori and Reba’s disability as socially constructed has its own limitations, which in this case is its construction of the twins as victims (albeit ones who are actively renegotiating their status) of a society that fails to recognize or include them. While the film showcases the many ways in which Lori and Reba move beyond society’s assumption that their shared body is faulty, it also positions the girls as victims of a society that fails to accommodate them. In this way, it shifts the source of victimization.

While this documentary is progressive, it is still limited in scope. Because it does not focus on the girls’ past—but gives just enough information to pique the interests of viewers—it draws even more attention to it. Reba does not like to talk about the decades that they spent at Hamburg, an institution for the severely mentally handicapped. When Lori begins to discuss this part of their lives—or Reba’s spina bifida—Reba says, “No more. There are some things I like to keep to me” (sic), thus maintaining that her past is private and that this information is part of what she considers her ‘private space’. She says only, “It doesn’t anger me, in the point that our parents put us there when we shouldn’t have been there. It angers me that the doctors... It angers me at the time it took them to get us out of there” (sic). Lori, initially the most hesitant about their release, is now determined to make up that time: “We should’ve had a better chance at life than we did. We were unfairly disadvantaged. We weren’t given that chance to prove and now we are, and we’re going full blast for it, so get out of our ways; we’re living our lives (sic).” Couser argues that this documentary avoids the “stock-in-trade of narratives” (2009: 30), “the clichéd trope of triumph over adversity—all too common in narratives of disability—which tends to reify the classification of individuals as disabled while congratulating them for succeeding nevertheless” (ibid: 56). However, I would argue that this is not entirely true. For a start, there is a sense that Reba and Lori have ‘triumphed’ over their past (and the medical establishment that unfairly disadvantaged them) when they left the clinic behind and established independent lives. Moreover, this ‘independence’ is counterintuitively presented as a form of social isolation. While it may be true that

the women are 'living their lives', they appear to be doing so—at least as far as the documentary shows—without friends or family. In fact, the only mention of family is through old photos of when Lori and Reba were much younger that are flashed quickly during one segment. Because of this absence, Lori and Reba are therefore made to seem 'abnormal' because they appear to lack the stability and comfort of 'normal' relationships. Those who appear in the documentary as 'friends' are those who know the girls because of their conjoinment. A few (nurses and aides) knew them from when they were residents of the institution; others are family members of those nurses and aides who also developed a relationship with Lori and Reba; and still others are medical professionals, including medical historian Alice Dreger and ethicist Catherine Myser.

While Couser applauds the "cast of interviewees", which does not include physicians who discuss their 'condition' or are concerned with their separation, the inclusion of academic voices in the documentary furthers the impression of an apparent lack of personal relationships in the Schappells' lives (ibid: 60). Dreger admitted being hesitant to appear as a "talking head" (2004: 132) in the "docu-drama" (ibid), as she calls it, but she acquiesced because Weisbrod seemed to be doing "something different" (ibid). She ultimately decided that the film succeeds in "dissolv[ing] the glass wall separating viewer and subject [...] [and] dissolving the line between the typically disempowered subject and the typically empowered medical expert" (ibid), yet the fact that friends and family are absent does work at least to an extent against this conclusion. This exclusion may be deliberate, part of the Schappells' strategy to maintain their privacy. When Lori and Reba speak about their family, which includes both parents and siblings, they refer to them as "very private". Couser has rightfully pointed out that this absence is open to interpretation. It could be a reflection of "their discomfort with the sisters' public self-presentation, or perhaps it is an expression of the sisters' autonomy and individuality" (2009: 61). Regardless of the actual reason, however, the absence of family and friends does present a conundrum for a film that attempts to present Lori and Reba as 'just like' everyone else. By not including this part of their private social lives, the documentary neglects to show how 'normalcy' is negotiated through their interaction with family and friends, an important omission in a film concerned with the social limitations of disability.

Do Lori and Reba, as Couser suggests, “triumph not over their impairment, which they accept, but over their disability—that is, ostracism and confinement” (2009: 57)? As far as one can tell by this documentary, they have not quite managed to do so, at least not in the areas of life depicted in the film itself. Lori and Reba have become independent in the sense that they live on their own and care for themselves (and they certainly do not hide from stares), but the film does not present them as socially successful. Lori, for example, went to a local college to earn the qualification that would allow her to be a ward clerk for a doctor, but she was unable to get a job in her field. Being able to work and “be independent”, which she defines as supporting herself, is an integral part of her identity. It is also, according to Dreger, a fundamental component of “American mythology” (2004: 32), which “equates individualism with independence, and interdependence with weakness” (ibid: 3). Lori claims that the first time she truly understood the extent of the discrimination “out there” was when she tried to get a particular job that was advertised in the paper. When she applied for it over the phone, the person was eager to meet her; impressed with her qualifications, the woman even said they had a job that Lori would likely get. However, as soon as Lori mentioned that she was a conjoined twin, the job was suddenly filled. When she did finally get a job, it was as a linen aide in the basement of a hospital, away from the public eye.

At the close of the 100-minute documentary, Lori claims that if she could change anything about her life so far, it would be that she is not married. Dreger places the blame for Lori’s inability to find a mate on society’s puritanical notions of sex and private spaces; these have caused their non-accessibility to traditional markers of success. This raises the question to what degree the documentary’s approach simply constructs the twins as different kinds of ‘victims’. Dreger’s explanation of society’s ignorance almost legitimizes, rather than challenges, these normative constructions. In doing so, the film seems almost to relax the conviction it has been establishing rather than suggest that society should adjust its ideas of what is considered ‘normal’. Because Lori and Reba have not been allowed access to some of the ‘normal’ markers of people their age: marriage, children, home ownership, and even careers, they are positioned as outsiders. Not being able to find a partner or secure a ‘regular’ job is a reality that Lori has not been able to

overcome, perhaps because she seeks a more traditional life. Her sister, on the other hand, has found success as a country music singer—a more untraditional choice—and she declares that she wants nothing to do with a husband or children. The film documents her time in a recording studio and shows clips of an episode of the *Jerry Springer Show* where Reba receives her official recording contract³¹. She is able to enjoy a level of success for which she strives, but mainly because she does not lay claim to any normative markers of a typical life trajectory; there is a sense here that aspiring to be ‘normal’ is more difficult than aspiring to be a celebrity. It is hinted at that Reba’s minor fame as a singer comes more as a result of her difference rather than in spite of it. In “The Dime Museum Freak Show Reconfigured as Talk Show” (1996), Andrea Stulman Dennett examines a number of similarities between the freak show and the television talk show,

an environment in which dysfunctional human beings parade themselves in front of an audience. [...] Although today’s talk shows promote themselves as “discussion programs” and do indeed occasionally address a politically important issue, their basic appeal is voyeurism. (320-1)

Dennett is critical of these programs, proposing that they are reconfigured freak shows. As such, the talk show is “about spectacle: it is a place where human deviance is enhanced, dressed, coiffed, and propped up for the entertainment of a paying audience. The freak show is about relationships: *us* versus *them*, the normal versus the freaks” (ibid: 324, her emphasis). This documentary seems to anticipate this criticism and uses filmed commentary from Dreger to refute potential arguments against the legitimacy of Reba’s musical success and her choice to appear on *The Jerry Springer Show*. She reminds the audience that people with extraordinary bodies, including models and athletes, have always used their bodies as capital in a variety of ways, so if these are accepted uses of an extraordinary body, then why would it be unacceptable for Reba to take full advantage of her exceptionality? She also states in her commentary that what Jerry Springer does is particularly subversive because he does not treat them with

³¹ Lori and Reba have appeared on *The Jerry Springer Show* on several different occasions over a number of years beginning in 1996. In “The Return of Lori and Reba,” an episode that aired originally on May 15, 2002, Springer focused on the girls’ sense of private and public space, and asked a number of questions about their dating history and intimate contacts. He also shared ‘Springer Cam’ clips of a date that Lori had gone on the night before and brought the date out to be interviewed on the show.

pity. She articulates further the positive aspects of talk shows for people with unusual anatomies in *One of Us* (2004):

I began asking people with unusual anatomies how they felt when they appeared on the shows, and nearly all of them found it an extremely positive, even empowering experience. Having been taught to hide their “shameful” anatomical difference, they saw such shows as an opportunity to be “out” and proud of who they are. They were treated by host and audience as authorities on an important experience, as people worth talking and listening to—as *respectable adults*. [...] While medical documentaries about normalization tend to infantilize people with unusual anatomies, talk shows often do exactly the opposite, raising issues of sexuality, professional occupation, and the like. (126-7)

In the clips that are shown of Lori and Reba’s appearance on *Jerry Springer*, the audience does not ask questions about Reba’s career, but focus instead on their conjoinment. One audience member says, “I’d just like to commend you both because if I had a brother that I had to stick with the whole time, I’d kill him.” This is certainly not pity, but it does, at least to a degree, follow the conventional trope of ‘triumph over adversity’ that Couser mentions, and it is related to Goffman’s assessment of “mixed contacts” (1985: 12) between “normals and stigmatized” (ibid). Goffman maintains that one of two feelings arise in stigmatized individuals when they find themselves in social settings with ‘normals’:

[T]he stigmatized individual is likely to feel that he is “on,” having to be self-conscious and calculating about the impression he is making, to a degree and in areas of conduct which he assumes others are not. Also, he is likely to feel that the usual scheme of interpretation for everyday events has been undermined. His minor accomplishments, he feels, may be assessed as signs of remarkable and noteworthy capacities in the circumstances. (ibid: 14)

While one cannot speculate what Reba feels during this encounter with a television audience, it is plausible to argue that both her sense of difference and her sense of her own celebrity make her feel ‘on’. More importantly, even if she does not see her accomplishment as something she has achieved despite (or because of) her conjoinment, the audience may position her in that way. Their comments indicate that they see her success as a relational component of her conjoinment.

The documentary concludes with the music video of Reba’s cover version of the song, “The Fear of Being Alone”. Couser sees the final scene as “celebratory”

(2009: 64) in that it “takes the twins decisively out of the freak show and into the celebrity culture of their time—in recognition of Reba’s genuine, if minor, fame, and in defiance of the distancing emphasis on the grotesque and anomalous” (ibid). Alice Dreger calls the idea of a music video “brilliant” (2004: 132). I, however, read it as ambiguous at best. The lyrics describe how two people come together briefly and are about to part when one decides to use “that word” (presumably ‘love’). The singer warns that it is not love the person feels; it’s merely ‘the fear of being alone’. In using the song to end the documentary, the audience is reminded that Lori and Reba have “obtain[ed] from [each other] something akin to the stalwart companionship, understanding, and unconditional love many others find primarily through committed romantic partnership” (Dreger 2004: 49). Indeed, the ending of the documentary attempts to show that Lori and Reba are complete because of their difference. However, the suggestion that Lori and Reba’s companionship *replaces* a romantic partnership reinforces the feeling that—while Reba is perhaps more successful because of her conjoinment—Lori is far less likely to experience many of the things she dreams of, including having a husband and children, and therefore has to accept the relationship with her sister as a substitute. The possibility that Lori might establish the romantic relationship she desires *in addition* to finding happiness in her relationship with Reba is closed down. Instead, the ending implies that Lori should find comfort in the fact that her conjoinment offers a suitable alternative to the life she desires. As a result, the stereotype that disabled people desire but are ultimately unable to attain romantic relationships and other markers of ‘normalcy’ is reinforced. Lori is presented as a victim of the close-minded society that Alice Dreger discusses in her filmed commentary. This is the inherent difficulty with representations of disability that adhere to a strictly ‘social model’ of disability. While they undoubtedly go a remarkable distance in shifting the locus of disability from the individual person onto society, they shift the source of victimization. Lori and Reba may no longer be victims of a medical regime that is trying to control their anomalous bodies, but they are still caught in a cycle of victimization. They are, at least for unassuming viewers, victims of society.

Joined for Life and Joined For Life: Abby and Brittany Turn 16

Abigail and Brittany Hensel are dicephalic parapagus³² conjoined twins, born on March 17, 1990. Because the odds that both girls would survive separation surgery were unfavorable due to the intricate connection of their bodies, their parents immediately rejected surgical intervention. Abby and Brittany have two hearts, two sets of lungs, two stomachs, and two separate spinal cords, but they share part of their intestines, a single bladder, and one set of reproductive organs. While the twins can do certain things (writing, for example) simultaneously, any activity requiring coordination (walking, typing, running, clapping, sports) is an act of balance and intuition; Abby controls the right side of their body, while Brittany controls the left, and each has no sensation of the other's side of their body. Other than the body they share, the Hensels have admittedly different individual personalities; they have different styles and interests; they excel in different school subjects; and they also prefer different foods. Most of their childhood was spent out of the public eye until they were featured in a photo editorial in *Life Magazine*³³ at age six. Their parents, Mike and Patty, have carefully controlled their media appearances, choosing what they have called "reputable" programs, magazines, and interviews that they feel have the potential to educate the public about their children (JL)³⁴. When the girls turned 11, they decided "as a family" to allow cameras to document a year in their lives (JL). This footage became *Joined for Life* (2002), directed by Bill Hayes. Four years later, they invited cameras back into their home to film *Joined for Life: Abby and Brittany Turn 16* (2006), directed by Rachael Pihlaja, a follow-up on the girls' progress in the year leading up to their sixteenth birthdays. While the two documentaries have significant differences, they are clearly meant to be read as a series, with the sequel updating the viewers about the girls' progress as they move towards maturity.

³² Dicephalic Parapagus twins have fused bodies, but each twin has his/her own separate head.

³³ In *Staring: How We Look* (2009), Rosemarie Garland-Thomson provides a more extensive analysis of the images in *Life Magazine*.

³⁴ To maintain a distinction between the two documentaries, I will use 'JL' to indicate a quote from *Joined for Life*, and I will use 'JL2' to indicate material from *Joined for Life: Abby and Brittany Turn 16*.

The obvious difference between Lori and Reba Schappell and the Hensels is their age and background. While the Schappells are adults, living and surviving on their own after years in an institution, Abby and Brittany have had average childhoods. Until 2008, when they began attending Bethel College in St. Paul, Minnesota, they lived with their parents and their two siblings in New Germany, Minnesota. Their lives largely revolved around their close-knit family and small community, meaning that they rarely ventured beyond their hometown; they attended small schools, played a variety of sports, enjoyed time with friends, and participated in activities typical for pre-teens and teenagers.

In *Vulnerable Subjects: Ethics and Life Writing* (2004), Couser expresses a number of concerns about ethics in contemporary life writing that are relevant to other biographical 'texts', including documentary. First, he defines 'vulnerable subjects' as "persons who are liable to exposure by someone with whom they are involved in an intimate or trust-based relationship but are unable to represent themselves in writing or to offer meaningful consent to their representation by someone else" (xii). By this definition, the Hensel twins are potentially vulnerable in that they are too young to provide legal consent to appear in either documentary; that permission must be granted by their parents. The girls "rely wholly on their trust in their collaborators" (filmmakers, and their parents in particular) (ibid: 17), and they are particularly vulnerable because of the "emotional intimacy [and] relational proximity" to those collaborators (ibid: 16). In other words, lacking the knowledge and experience to judge the merits of the documentaries for themselves, they must trust their parents to decide, especially in the first documentary in which they are only 11 years old. They must also trust their parents—and others who are authorized to divulge information about them—to respect, and even preserve, the intimate details of their lives. This involves a delicate balance for ethical filmmakers. On one hand, the documentaries must engage an audience. On the other hand, they must respect what the girls' parents have set out to do: show the public that Brittany and Abby Hensel are "two individuals that have the same hopes and fears as any other child their age" (JL) and help people "understand Brittany and Abby when it's not [their] own little community anymore" (ibid).

Couser's concern in the case of vulnerable subjects is with autonomy, defined in this case not as total independence, but as a "transpersonal phenomenon [...] to be exercised within relationships of interdependency" (2009: 19). I would argue that Abby and Brittany's autonomy is preserved as far as it can be in both documentaries, as they "have the opportunity to exercise some degree of control over what happens to their stories"; first and foremost, they are the primary voices in their documentaries (ibid). Second, it is made clear that the girls were active contributors in the decision to film them. *Abby and Brittany Turn 16* begins with an assertion of their agency. According to the narrator, "Abby and Brittany have chosen not to appear on all of the talk shows or do interviews for the many magazine who make requests" (JL2). Instead, they decided that they did not want to live their lives in the spotlight, but rather give updates periodically about their progress. Their mother supports that decision, stating, "I've had TV people come up to me and say that I owe the world more of an explanation regarding Abby and Brittany. I don't owe the world nothing, and Abby and Brittany don't owe the world anything either" (ibid). Clearly, they (with their family's support) control how and when their story is constructed and circulated. Together, these documentaries "alert [viewers] to ways in which supposedly vulnerable subjects may assert power and agency greater than might be expected" (Couser 2009: 18). Those ways will become more apparent as this chapter progresses.

In the first ten minutes of *Joined for Life*, the first of the two films, viewers are introduced to the ways through which Brittany and Abby's story will be told: home video (some of it filmed by the girls themselves); interviews with family, doctors, coaches, and friends; photographs; and an unseen narrator who provides commentary or explanation. An off-screen narrator, who is noticeably absent from the Schappell documentary, functions to articulate conclusions that the Schappells, as adults, can draw about their own experiences; she often interrupts the narrative flow of the Hensel documentaries to remind viewers that the girls are typical or 'normal'. This 'normalcy' is a carefully and consciously constructed attribute, rather than a given. It could be argued that in using a narrator to describe what should be obvious, the film almost defeats what it tries to achieve: to show the Hensels as unremarkable—just like any of the story's viewers.

The other noticeable difference between these documentaries and *Face to Face* is the type of interaction that viewers become accustomed to seeing. Lori and Reba frequently venture outside of Reading, Pennsylvania; their travels and interactions with society at large are foundational elements of their story, yet interaction with ‘friends’, people with whom they have connected outside the condition of their conjoinment, is absent. While Brittany and Abby do fly to Houston, Texas in both films to visit Tamara Vogt, a friend whose conjoined daughters died shortly after birth, they admit that they prefer to stay within the confines of their small Minnesota community. In fact, when the location for an upcoming family vacation is debated, Brittany becomes anxious at the prospect of a trip to Disneyland because she doesn’t “like being around people, a lot of people” (JL2). Unlike the Schappells, Abby and Brittany have not yet become effective handlers of the staring encounter, and the cause of this is ambiguous. While Brittany’s reaction could be read as typical for small town children—or even children in general—it is implied by the way this scene is situated within the documentary that she worries about how others will react to her. She “anticipatorily respond[s] by defensive cowering” (Goffman 1986: 17), because she has learned “that mixed social situations make for anxious un-anchored interaction” (ibid: 18).

Because filmmakers keep Abby and Brittany simultaneously in the central and peripheral positions, viewers are once again implicated in the deconstruction of the spectator/spectacle dynamic. Both *Joined for Life* and *Abby and Brittany Turn 16* align their audience with the girls by placing them within a narrative that includes family and friends; for all intents and purposes, they live a life that is insipidly familiar. Because the viewer is invited to identify with the twins by finding commonalities, he or she is positioned to see them as completely ‘normal’ despite their obvious visual difference. For example, the first documentary highlights their interest in sports, especially Volleyball and Softball. It also shows them visiting the dentist, enjoying a day off of school because of snow, as well as functioning in their everyday school routines as ‘normal’ pre-teens. At several points in *Joined for Life*, the documentary camera is replaced by the girls’ handheld camera. In one scene, Abby and Brittany demand that their parents “not come in” as they run into their room, turn their camera on, and directly address viewers,

explaining that they are nervous about the next day's volleyball tournament. In another scene, they turn the camera upon themselves and tell their audience: "This is how we look when we're sick." In speaking directly to viewers, and in showing even unknowingly that their lives are quite ordinary in small ways, the girls build a level of familiarity and intimacy that helps them to maintain their subject positions. Establishing connections between them and the viewers who see them diminish both physical and psychical distance.

In the second film, *Joined for Life: Abby and Brittany Turn 16*, Abby and Brittany begin by listing for viewers the top ten ways they've changed since the last film. Their current list of interests include such activities as talking on the phone, driving, attending high school, listening to music, shopping, playing online, working and talking more. As the narrator points out, the most noteworthy thing about this list "is how typical it is for their age. Being conjoined has presented astonishingly few obstacles to leading a normal life" (JL2). Once again, the familiarity helps establish a connection between the Hensels and viewers, which prevents them from being seen as outsiders. However, the narrative can be said to work against itself. By insisting on Brittany and Abby's 'normalcy', the narrator shows that 'normalcy' is a category that is laboriously constructed rather than a given.

Brittany and Abby assert power and agency in both documentaries through their insistence on their individuality. For this, they do not require the help of a narrator; they are not only collective agents in the sense that they determine how their story will be told, but they are also agents in the sense that they manage to assert themselves as individual subjects despite and because of their shared body. In her article "*This Body Which is Not One: Dealing With Difference*" (1999), Margrit Shildrik examines the ways that "those who do not, indeed cannot, unproblematically occupy the subject position" (79) challenge the Western notion of the self as "distinguished from the other, to be ordered and discrete, secure *within* the well-defined boundaries of the body" (ibid; her emphasis). Like the Schappells, the Hensels suggest that autonomy does not define their subjecthood. When they are asked whether they would choose separation for themselves, they simply respond "no" (JL2). Abby follows up by explaining, "We never wish we were separated" (ibid), and Brittany says, "We don't know any other way" (ibid).

Abby and Brittany are able to do many of the same activities as their peers *because* of their shared body; in their case, separation would have left each of the girls with half of a body, thereby limiting the different ways in which they could express their individuality. Their sense of individuality, which their pediatrician, Dr. Westerdahl, reminds viewers is very different from our own (she assumes a normative viewer) is built on their conjoinment; the Hensels see themselves simultaneously as one and two. In general, when they email and send instant messages, they refer to themselves collectively as “I”, but when they disagree, they indicate who is speaking. Those who are closest to them, including their parents, siblings, and friends also testify to their differences. While Abby is called “feisty” (JL2), the “boss of the house” (ibid), Brittany is known to be “easygoing” (ibid), “easy to talk to” (ibid) and the “goofy one” (ibid). Even their English teacher, Kevin Boozikee, notes:

They are very different. I would say Abby is a little more outgoing. I really appreciate her assertiveness, and her demand to know more and ask more questions. I find myself probably joking with her more a little bit. With Brittany, I think she’s a little more quiet, a little more reserved, thinks through some things, maybe not quite as assertive, certainly more contemplative. (ibid)

Finally, Minnesota law recognizes them as two individuals. On the day they turned 16, they passed their licensing test, and officials had to decide how to issue them. Ultimately, the Minnesota Department of Transportation decided on a separate license for each girl. Clearly, this documentary shows the girls as two wholly separate individuals. They are more than their shared body, yet that body also contributes to their personal sense of individuality.

As was the case with the Schappells, the Hensels do endure ‘baroque staring’ especially when they venture outside of their hometown, yet by the time this happens at the end of the second film, the television audience has adjusted to their uniqueness; they have become accustomed to them even as passersby have not. Both on the airplane and in the Houston airport, several people turn to look at them as they pass. A few even take photos—something that Abby and Brittany rightly detest. According to Abby, “We don’t mind when people ask questions. That’s better than taking pictures or being mean about it” (ibid). They become noticeably upset, for instance, when they realize that a cameraman is filming them

without their permission while they're on the field at an Astros game. Even though the narrator explains, "this is the risk they take when they leave the protective environment of home" (ibid), the comment provides little consolation to an audience of "initiated viewers" (Garland-Thomson, 2009: 114). When Patty Hensel makes clear the fact that "It drives them crazy because they feel like they're being violated" (JL2), the audience is likely to take issue with the cameraman's exploitative gaze. Unlike the invisible documentary camera, which has positioned the girls as agents of their own story, this cameraman treats them as a spectacle. However, as was the case in *Face to Face*, the spectacle/spectator dynamic is shifted in this scene; the cameraman (being shot by the documentary filmmakers as he films the girls) becomes the outsider and object of denigration.

A distinguishing feature of both *Joined for Life* and *Abby and Brittany Turn 16* is the portrayal of the medical interventions that Abby and Brittany face. While neither documentary focuses exclusively on the medical aspects of their conjoinment, the inclusion of these realities helps the audience to see conjoinment as both material and social, thereby reflecting the current movement in disability studies to find a compromise between models of disability. The doctors who are interviewed not only discuss how the girls are completely like their peers, but also what unique realities they face because of their conjoinment. Halfway through *Joined for Life: Abby and Brittany Turn 16*, the narrator interrupts this story about 'normal' girls to mention medical issues that "loom" ahead (JL2). Abby and Brittany face immediate surgery because of their worsening case of scoliosis—a condition that puts pressure on their hearts and diminishes their lung capacity. While viewers have grown accustomed to occasional glimpses of scans and technical explanations of the girls' conjoinment provided by doctors, this is the first time that their physical reality transforms them into patients in need of medical intervention. Just as viewers were permitted access to scans and x-rays in the medical documentaries previously discussed, here too they are shown x-rays that display the twins' fused ribcages and the severe outward curvature of their spines. In addition, computer program models detail what will occur during the surgery. The difference, of course, is that this surgery is not about separation. It is not about eliminating their difference, but about making adjustments so that they can thrive despite their difference.

It is noteworthy that Abby and Brittany refuse to be shown during their recovery following the surgery. Their mother is careful to honor their wishes that “the camera [not be] on them while they are recovering” (ibid). Thus, the girls continue to exercise control over their story; the only image of them in the hospital is the one of them leaving. In the first documentary, at just 11 years old, they were eager to share with the audience when they weren’t feeling well—to give a visual impression of their illness—but they seem here, in the latter film, to have developed a heightened sense of their private space. Despite the comparative distance with which the girls’ medical problems are treated, this part of the documentary is an important one in that it shows directly how their impairment limits them. Rather than ignore the physical problems that result from conjoinment, the documentary posits disability as both a biological reality and a social construction. In doing so, it goes a step further than the Schappell film, hinting at a more complex understanding of disability.

Because Abby and Brittany are young, documentaries dealing with their lives cannot ignore questions about their future. Instead, they confront issues directly and anticipate concerns that the audience may have. Unlike medical documentaries, however, that use the future as an illusive point of ‘normalcy’ that is usually conflated with separation, the Hensels seem to celebrate the unknown. *Abby and Brittany Turn 16* uses an approach similar to the one used in *Face to Face*; during a scene of the girls at a regular check-up with their primary care doctor, the narrator interjects to address directly the issues that are presumably on viewers’ minds: “their future, from questions about college and careers, to deeper issues such as their health, future relationships, could they become mothers” (JL2). Dr. Westerdahl assures viewers that she suspects everything will “go normally” (ibid) if the girls choose to have a child, and she admits

it would be nice to predict their future. Everyone asks ‘how long’. You know, ‘what do you expect for the future for these girls?’ Well, I expect them to live healthy, normal, happy lives, but it would be sort of nice to know, you know, how that circulatory system is going to play out, how the respiratory system is going to play out, how are they going to adapt, you know, and how are they going to function. (ibid)

Later, the narrator introduces the subject of dating, and Brittany and Abby explain, “The whole world doesn’t need to know who we’re dating, or what we’re

going to do and everything” (ibid). Here again, they clearly assert an understanding of personal and private space, which they protect. As for motherhood, their own mother says that each has expressed an interest in becoming a mother, but Abby and Brittany are not ready to think about it seriously: “We haven’t thought about how being moms is going to work yet. We’re just 16. We don’t need to think about that right now” (JL2). Again, they reiterate their position as ‘normal’ teenagers who do not want to discuss an illusive future.

At the same time, the few clues that are given about the girls’ future are strikingly heteronormative, anticipating childbirth and reproductive sexual intercourse, most likely in the framework of heterosexual marriage. This implies that the girls’ futures are not as ‘open’ and ‘free’ as it might at first appear. In this sense, the two films about the Hensels do not simply “[trace] their lives chronologically from the initial shock of their birth”, but the very fact that they offer a look at the Hensel twins’ lives unfolding, hints at a more traditional, linear model of the individual life course that inscribes its own sets of norms (Couser 2009: 57). Thus, while these documentaries avoid the medical gaze and the focus on the separating ‘cut’ as the culminating moment of development and the focal point of narrative drive, their presentation of a social model of disability also threatens to impose a set of values and norms, as well as a specific narrative trajectory, on the lives and experiences of conjoined twins. Moreover, it is the feared exclusion from these normative markers of development that potentially positions them in the role of the victim because, as Dreger has argued, there seems to be “anxiety about conjoined children’s future sexuality. [...] [S]exual anxiety forms a prominent and convoluted theme in medical and media narratives of conjoinment and separation” (2004: 62). In presenting a normative timeline of life (over the course of the two films) and praising how the girls are meeting certain benchmarks of development, and then ending the second documentary with a focus on questions of marriage and childbirth, it becomes evident that even documentaries focusing on social models of disability inadvertently fail to challenge understandings of ‘normalcy’ and deviance. They do not pay attention to the way in which ideologies of gender and sexuality interact with and inform constructions of health and disability.

Ultimately, then, the work begun by documentaries about Lori and Reba Schappell and Abigail and Brittany Hensel needs to be taken further. What these documentaries do is to point to the ineffectiveness of dichotomies. Conjoined twins—or physically different people in general—do not fit neatly into any binary and therefore enable a reconsideration of what it means to be a different or other body in a specific social context. Living *in* a body, living *with* a body, and living *as* a body, conjoined twins draw attention to the need for a complex understanding of embodiment. It is not surprising, then, that contemporary life narratives of conjoined twins often do not subscribe wholly to either a medical or social model of disability, even when they gravitate more strongly toward one approach, but begin to recognize the disabled body as a lived body. What the documentaries discussed in this chapter fail to address fully is that the disabled body, as a lived body, is determined by understandings of physical health, and also by other ideologies of ‘normalcy’ including those of economic and sexual wellbeing. If the Schappells and the Hensels at times inadvertently appear as victims in the films discussed, this is because the documentaries do not fully emancipate themselves and their subjects from stereotypical models of a normative life course determined by traditional notions of economic and romantic ‘success’. *Face to Face* does not address the physical realities of the Schappells’ conjoinment, and the Hensel films offer only a limited view. The result is that these documentaries manage to shift the emphasis from the body of conjoined twins to the perception of those bodies by society. However, in my view this approach is not enough. While it might “change assumptions made about people born with unusual anatomies”, it does not offer a radical enough approach to understanding difference (Dreger 2005: 6).

The chapters that follow will deal with contemporary novels that take into consideration not only disability, but also other categories of difference. In these instances, conjoined twins are positioned as a relational compromise between binaries that may serve to destabilize binaries as a whole. Rather than shift attention from one paradigm to another, the novels work from the middle in order to subvert normative assumptions.

Beyond the Medical/Social Binary: Disability & Identity in Contemporary Fiction

The final chapters of this thesis demonstrate how disability studies (and questions of sexuality in chapter five) can be significantly enriched by a consideration of contemporary fictional representations of conjoined twins. This turn from documentary to fiction no doubt raises questions concerning genre, however as I discuss at length in the introduction to chapter two, documentary is already a hybrid genre—one that is simultaneously educational, informative, and entertaining—and blurs the boundaries between fiction and fact. To create a captivating story that viewers are interested in seeing, for instance, documentary already uses a number of narrative techniques usually associated with fiction. Conversely, fiction cannot be contained within narrowly defined parameters either, as it too can be educational and informative and can powerfully affect the reader's understanding of the world outside of the fictional realm. If, as Rosemarie Garland-Thomson suggests, "we accept the convention that fiction has some mimetic relation to life, [then] we grant it power to further shape our perceptions of the world, especially regarding situations about which we have little direct knowledge" (1997: 10). Her statement is equally applicable to documentary, which does not simply represent reality, but also shapes the viewers perception of it. The point here is that while the chapters are delineated by genre, this does not imply that it is possible to draw a fixed line between them. The fact that a Nip/Tuck episode is discussed alongside medical documentaries, for instance, points to the permeability of categories of genre; this episode straddles the line between fact and fiction, using real life conjoined twins and rehearsing many of the operating room conventions that I point out in chapter two; yet as a serial drama, it is clearly intended to be entertaining and does not claim to represent reality truthfully.

The chapter organization of this thesis was therefore not driven primarily by genre, but, rather, by the fact that the documentaries deal more fully with individual models of disability (though they do at times, as I point out throughout the chapters, shift temporarily to the opposing model), while the novels offer a more balanced view, opening up the possibility of a more complex approach to

disability. In keeping with the novelistic emphasis on introspection and character development, fictional representations of conjoined twins focus on individual experience—what it means to live as, in, and with a particular body—and the way in which conjoined twins negotiate a very particular cultural and social context. Placing greater emphasis on the material body and individual struggles, including the relation between physical conjoinment and other forms of difference, such as sexual or racial dissidence, contemporary fiction draws attention to the relationship between the individual and the collective. In doing so, it creates what disability scholar Susan Peters refers to as an “enduring hyphenation” in which personal identity and the lived body form a dynamic bond with shared communal experience (1996: 231). This is not to say that the documentaries discussed do not occasionally achieve the same, but they tend only to do so fleetingly.

A consideration of audience is also important to this discussion of genre. Because literary fiction lays little or no claim to representing reality, we may assume that it is more open to a multiplicity of readings, inviting a more self-reflective engagement of the reader with the text. Documentary, on the other hand, has an automatic expectation of representing reality. Positioning itself as referential, the documentary can turn viewers into passive recipients of information, yet, as I discuss at length in chapter two, this view is problematic. First, both documentary and literary fictions are hybrid genres, as I discuss above. Second, it is wrong to assume that documentaries always reinforce norms, while literature is infinitely open or plural. Both documentaries and literary fiction have the potential to reinforce ideologies and both can be transformative and encourage critical thought. Third, with regard to audience, viewers and readers alike have the potential ability to challenge what is represented and remain open to a variety of interpretations. Both become part of the circulation of meaning. In his work on the spectator, Rancière positions the viewer as an active agent—someone who “observes, selects, compares, interprets” (2009: 13). The same can be applied to the reader, who engages actively with literary texts.

Balancing the Medical and Social Models of Disability

Whereas the ‘medical model’ of disability is open to criticism because medicine, in general, is “becoming a major institution of social control, [...] the new repository of truth, the place where absolute and often final judgments are made by supposedly morally neutral and objective experts”, an exclusively social interpretation of disability also poses a number of difficulties (Zola, 1972: 487). First, the relationship between the physical and the cultural is more complex than the social model of disability implies. After all, as Niall Richardson maintains, “the distinction between physical impairment and the cultural label of disability may not always be as easily distinguished as the social model would maintain” (2010: 171).

Second, while the juxtaposition of impairment and disability offered by the social model is politically empowering in that it draws attention to the social factors that create disability in the first place, there is an inherent risk in upholding the strict dichotomy between impairment and disability. Tom Shakespeare challenges the social model on this basis, warning that the danger of a strictly social constructionist approach is in its radical rejection of the physical. While the social model of disability was groundbreaking in its ability to “[dislodge] the deep-seated idea that disabled people are defined by their incapacity” (Shakespeare, 2006: 31), it is also immediately implicated in a new, equally problematic dynamic that upholds a notion of “disability as nothing whatsoever to do with individual bodies or brains” (ibid). Shakespeare therefore argues for a rejection of the social model of disability, recommending in its place a holistic re-conceptualization of disability as interaction between individual bodies and the social environment in which they are placed:

The experience of a disabled person results from the relationship between factors intrinsic to the individual, and extrinsic factors arising from the wider context in which she finds herself. Among the intrinsic factors are issues such as: the nature and severity of her impairment, her own attitudes to it, her personal qualities and abilities, and her personality. Among the contextual factors are: the attitudes and reactions of others, the extent to which the environment is enabling or disabling, and wider cultural, social, and economic issues relevant to disability in that society. (ibid: 56)

Similarly, Alexa Schriempf proposes an “interactionist paradigm” (2001: 61) of disability theory that regards impairment as more than a “meaningless biological function” (ibid: 65).

Moreover, Liz Crow—a self-proclaimed “proponent of the social model of disability” (1996: 56)—has called for a “renewed social model” (ibid: 65), one that considers more fully the complexity of impairment. According to Crow, the social model has been effective as a political strategy, confronting discriminatory practices and structures, but it has largely failed in representing disabled people on a personal, individual level. What she advocates in its place is a framework that offers “a more complete understanding of disability and impairment as social concepts; and a recognition of an individual's experiences of their body over time and in variable circumstances” (ibid: 65-6). Such a model would recognize and appreciate the value of the complexities of impairment and subjective experience,

acknowledg[ing] that people apply their own meanings to their own experiences of impairment. This self-interpretation adds a whole new layer of personal, subjective interpretations to the objective concept of impairment. The personal interpretation incorporates any meaning that impairment holds for an individual (i.e. any effects it has on their activities), the feelings it produces (e.g. pain) and any concerns the individual might have (e.g. how their impairment might progress). Individuals might regard their impairment as positive, neutral or negative, and this might differ according to time and changing circumstances. With this approach, the experiences and history of our impairments become a part of our autobiography. They join our experience of disability and other aspects of our lives to form a complete sense of ourselves. (ibid: 60)

Disability theorist, Susan Wendell, who was diagnosed in the late 1980s with chronic fatigue immune dysfunction syndrome, seeks an equivalent compromise between the social and the biological. In *The Rejected Body: Feminist Philosophical Reflections on Disability* (1996), she argues for a “social construction of disability” (45), which is an amalgam of the material and cultural:

I believe that in thinking about the social construction of disability we need to strike a balance between, on the one hand, thinking of a body's abilities and limitations as given by nature and/or accident, as immutable and uncontrollable, and, on the other hand, thinking of them as so constructed by society and culture as to be controllable by human thought, will, and action. We need to acknowledge that social justice and cultural change can eliminate a great deal of disability while recognizing that there may be much suffering and limitation that they cannot fix. (ibid)

Further, Hughes and Paterson challenge the impairment/disability dualism through their focus on the 'lived body' as a site where physical affliction and cultural narratives come together to constitute the experience of disability:

The impaired body is a 'lived body'. Disabled people experience impairment, as well as disability, not in separate Cartesian compartments, but as part of a complex interpenetration of oppression and affliction. The body is the stuff of human affliction and affectivity as well as the subject/object of oppression. The value of a phenomenological sociology of the body to the development of a sociology of impairment is that it embodies the addition of sentience and sensibility to notions of oppression and exclusion. Disability is experienced in, on and through the body, just as impairment is experienced in terms of the personal and cultural narratives that help to constitute its meaning. (1997: 334-335)

In *Disability Theory* (2008), Tobin Siebers echoes this claim, pointing out that while there are risks of "[r]estoring a sense of realism of the disabled body" (67), there are also specific benefits for disability studies of accepting "bodily reality" (66). Like his contemporaries, he argues for recognition of the body as

first and foremost, a biological agent teeming with vital and often unruly forces. It is not inert matter subject to easy manipulation by social representations. The body is alive, which means that it is as capable of influencing and transforming social languages as they are capable of influencing and transforming it (68).

Similarly, Snyder and Mitchell propose a 'cultural model' that

recognize[s] disability as a site of phenomenological value that is not purely synonymous with the process of social disablement. Such an emphasis does not hide the degree to which social obstacles and biological capacities may impinge upon our lives, but rather suggests that the result of those differences comes to bear significantly on the ways disabled people experience their environments and their bodies. Environment and bodily variation (particularly those traits experienced as socially stigmatized differences) particularly impinge upon each other. (2006: 6-7)

Finally, Chivers and Markotic, through their work on filmic representations of disability, seek to "shift the 'either/or' structure of disability studies to a 'both/and' model' model so that disability can be understood as *both* physical *and* social" (2010: 11).

This desire among disability studies scholars to find a more nuanced understanding of the relation between the individual body and its social context mirrors wider debates about the material reality and cultural signification of the body, which have been discussed in earlier chapters. Collectively, these disability

theorists and activists propose an understanding of disability that directly applies to contemporary representations of conjoined twins, as it points to the fact that conjoined twins are both subjects with uncommon bodies and individuals whose identities bear the imprint of social and often literal surgical construction. This chapter examines the ways in which novelists tackle these issues and demonstrates how literary writing critically engages with models of disability. It shows that the desire to find a compromise between the medical and the social model of disability finds expression in contemporary fiction, which has begun to promote an understanding of disability as a category of identity that is shaped simultaneously by the individual body and the meaning that the body has come to bear within a wider social context. The case of conjoined twins provides a compelling example of the ways that contemporary fiction is beginning to place greater emphasis on the lived body, moving beyond a medical and pathological model of disability while simultaneously resisting the reliance on a universal common experience associated with social models of disability. It is also, as this chapter will show, going much further in terms of opening up the representation of conjoined twins and disabled people more generally, in order to critique the process of representation as a whole.

Negotiating the Body: *The Girls* by Lori Lansens

The Girls (2007), by Lori Lansens, points to a possible reconciliation between models of disability by recognizing how the body as lived material reality and social construction directly influences identity. The two main characters of the novel are Rose and Ruby Darlen, the oldest living craniopagus twins. Abandoned by their mother shortly after birth, they are adopted by Lovey Darlen, one of the nurses who assisted with their delivery, and her Slovakian immigrant husband. The fact that the girls are joined at the head visually undermines the very idea of what it means to be a single subject in a culture where the head and brain are seen as the site of consciousness and the face is a mark of individuality. This particular form of conjoinment therefore presents in a particularly dramatic fashion the challenges conjoined twins pose with regard to subjectivity. Even Ruby recognizes the startling nature of their conjoinment. She says, "Staring is a fact of life when

you are a conjoined twin. I think especially when you're joined at the head, because that's when people really go Oh my God! Imagine that!" (71). There is a risk that craniopagus twins can be assumed to share thoughts and therefore share subjectivity, yet it becomes quickly obvious that Rose and Ruby are completely different; "[their] thoughts are distinctly [their] own" (5) and, as Rose explains, they are "more different than most identical twins" (ibid).

The novel begins with this account of the reality of a physical difference that threatens to undermine visually the girls' individuality, but also forces them to deal with (at times) difficult symptoms. The text does not deny the realities of their physical impairment, and Rose explains early on in the narrative what she and Ruby face on a daily basis: "I'm five feet five inches tall. When we were born, my limbs were symmetrical, in proportion to my body. Presently, my right leg is a full three inches shorter than my left, my spine compressed, my right hip cocked" (4). The girls experience "mild to severe neck, jaw, and shoulder pain" (ibid); their bodies are each strained in various ways, and "Ruby has a multitude of bowel and urinary tract problems" (ibid). In addition, as Rose explains,

Ruby and I share a common blood supply. My blood flows normally in the left side of my brain, but the blood in my right (the connected side) flows to my sister's left, and vice versa for her. It's estimated that we share a web of one hundred veins as well as our skull bones. Our cerebral tissue is fully enmeshed, our vascular systems snarled like briar bushes, but our brains themselves are separate and functioning. (5)

Despite these physical realities, which "profoundly restrict [their] lives", the novel shows how the girls have learned to handle their bodies despite (rather than because of) the medical treatment they endure (8). In fact, Rose maintains that she and Ruby "endure *because of* [their] connectedness" (52; her emphasis).

The medical approach to their physical difference, rather than the difference itself, is scrutinized throughout the novel. When Rose describes the way she and Ruby were brought into the world, for instance, she refers to their treatment by Dr. Mau, an "eminent craniofacial surgeon", as "hungry" (31). Other doctors who came from around the world to examine them are said to have "set upon" them, referring to the girls as "it" (ibid). Ruby, the smaller of the two, was called a "parasite" and Aunt Lovey "said Dr. Mau reminded her of a large black spider descending upon two little fruit flies" (ibid). Thus, the novel does not

present Rose and Ruby as victims of their physical condition; rather, they are presented as victims of doctors who seek to examine them in a bid to 'repair' their physical difference. The fact that they are treated as specimens points to the idea that medicine actively constructs rather than 'corrects' their difference. Rose recalls being taken to the Children's Hospital of Philadelphia at age six to be examined by Dr. Mau. She explains:

We endured dozens of X-rays, and needle pricks, and electrodes, and swabs, and other procedures I wasn't familiar with, and after several hours we were taken to a large operating theatre where Dr. Mau and a group of ten other doctors waited. [...] We were lying naked on two large gurneys that had been pushed together. [...] I remember that, after an hour or so of Dr. Mau's picking and prodding and talking to the other doctors in a foreign language, his black eyes had found mine. (79)

Her description of Dr. Mau and the medical procedures that she and Ruby experience contribute to an understanding of medicine as a system of power that constructs and defines physical difference. Medicine is portrayed as an imposing force—one that places the girls in a position of vulnerability.

As the novel progresses, however, this potential victimization of Ruby and Rose is rendered problematic, as Lansens shows that their bodily difference is integral to their identity and agency. Just as doctors could not provide an answer to their intricate conjoinment at birth, they cannot save the girls from the brain aneurysm that will ultimately kill them both. Before their thirtieth birthday, Rose is diagnosed with an aneurysm and she gradually deteriorates during the course of the novel. Importantly, the condition is described as hers alone although it also affects her sister. As a result, Rose experiences myriad physical symptoms, including weakness in the legs, debilitating headaches, and hallucinations, but her body is the catalyst for the narrative. Because Rose reads and narrates her life *through* her body, physical difference emerges as a force contributing to the narrative process. Rose is writing because she understands that her death is a matter of time, and "the best the dead can hope for is to be conjured from time to time, through a note of haunting music or a passage in a book" (5). Here, physical impairment is not only acknowledged, but it is also presented as the precondition and motivation behind the girls' desire for expression and self-narration. It is in the face of and because of their impending joined death that Ruby and Rose narrate their stories. Thus, the physically impaired body is presented as the very

site of agency and possible resistance both to their objectification through the medical gaze and the way in which their physical condition threatens to undermine their individuality.

Indeed, the differences between Rose and Ruby are affirmed through the narrative situation. Rose begins her narrative by sharing details about her life on the farm. Certainly Ruby is part of this story, but Rose is clear that she wants to share this “story of *my* life”, not our life (6; her emphasis). Rose also advises Ruby “to write about [her] life, not just [their] life, and to share [her] own thoughts and memories of the past” (72). Several chapters into the novel, Ruby begins her part of the narration, questioning how it is possible for her conjoined sister to write an autobiography “when she hasn’t lived her life alone” (66). She recognizes the complicated dynamics of their unique anatomy, but she also explains that it is “important to have some say in the story of [her] sister’s life because although [they are] conjoined twins, and technically have parallel vision, [they] don’t always see eye to eye” (66-7). Like Rose, Ruby understands that she is an individual and decides (reluctantly at first) to tell the story of their lives from *her* point of view. While Rose begins with the story of their birth and recollections of their childhood, Ruby’s narrative starts in the present. Announcing to the reader that “we are dying”, it is Ruby who reveals that Rose has been diagnosed with an inoperable aneurysm (70).

The negotiation of Rose and Ruby’s individual narratives also points to the need to reconcile different understandings and experiences of the body. Reflecting on her conjoinment, Rose states, “I understand that I am *me*, but that I am also *we*” (8; her emphasis). The statement ‘I am *me*’ indicates Rose’s unique individual experience of her body. In saying ‘I am also *we*’, however, Rose also embraces the idea that her body is not hers alone and that its meaning is always shared. Because of her conjoinment, Rose literally shares her body with her sister and it is through their individual narratives that the meaning of the body is negotiated and conveyed to the reader. More generally, the statement ‘I am also *we*’ points to the fact that the body is always located in a certain cultural and social context, so that its meaning is communal, going beyond the individual person (or persons in the case of conjoined twins). Rose’s willingness to think about herself in terms of the first person singular as well as the first person plural indicates the move towards

a more complex understanding of the body as both the site of immediate individual experience as well as social inscription.

Overall, the novel presents an understanding of the disabled body as a material reality that is actively and systematically constructed by and through social relationships. What is deemed 'normal' and 'abnormal', for instance, is exposed as radically contingent. When Lovey and Stash move the twins to a country home, for example, the girls are "sheltered in the essence of normal" (43). Because "Lovey [wants] more for [them] than just survival" (9), she encourages them to be self-sufficient and independent. The girls learn how to negotiate their shared body together while also maintaining a sense of themselves as individuals. As a result, Rose recognizes herself as simultaneously self and other, and Ruby admits that she has "never [dreamed] of being separated from Rose. Never" (76). Within their home, they experience their bodies as 'normal', and they cannot conceive of a life different than the one they were born into. Reminiscent of Alice Dreger's argument that a stigmatized condition, "often function[s] as an inexplicable, essential, even cherished aspect of the self for those who do inhabit them" (2004: 47), Rose states, "we are normal to ourselves. It's normal for me and Ruby to be who we are and live as we do" (156).

It is when Rose and Ruby venture outside of their familiar surroundings or spend time with people who are not accustomed to them that they experience their conjoinment differently. Rose observes how she and Ruby "never will live anonymously. Because of [their] situation, people treat [them] like children, or the elderly" (103). She also describes the experience of being stared at and becoming aware of her physical difference because of the stare. At the same time, however, being stared at is also a 'normal' part of their everyday lives. When she and Ruby visit their birth mother's grave, she describes how people stare at them: "Of course, they were staring because we are conjoined, but they were also staring because we were a spectacle" (28). Importantly, Rose does not only see their physical difference as the spectacle; she also views Ruby's reaction to their mother's grave (she moans her name, Mary-Ann, repeatedly) as that which causes people to look. Later, when they stop at a restaurant, Rose explains how every public encounter involves staring. In fact, "[they've] been stared at so much in [their] lives [they] find it normal, and only really notice when [they] *haven't* been

noticed" (29; her emphasis). This explains why the girls are so distraught when they travel to Slovakia to visit Uncle Stash's family. They expect to be stared at, but they are initially greeted with indifference. Rose writes, "No one was staring. There was *no staring*. No craning. No peering. Nothing. It wasn't just odd or weird, it was frightening" (249; her emphasis). They soon realize, however, that they are being stared at, just not openly; Rose claims to feel an awareness that "they were all watching Ruby and [her] from behind, thinking [them] marvelous. And awful" (264). What they eventually discover is that they have arrived on St. Katarina Day. They are seen as good omens—reminiscent of pre-Enlightenment understandings of physical difference—when a sickly pregnant woman touches the spot of their conjoinment and subsequently delivers healthy babies. The girls become instant celebrities, and just as in the freak show, their cousin begins charging money for the locals to see and touch the girls. The girls' experiences in Slovakia show the extent to which cultural context determines the meaning of the body; in a society where unusual bodies are read as signs of wonder or miracles, for instance, the responses to Rose and Ruby's unusual anatomy are vastly different compared to the US. Even in the US, however, how the girls feel about their body changes depending on whether they are situated in the domestic sphere or in public.

In addition to presenting the body as a cultural construct, however, the novel also draws attention to the fact that the girls experience their body in a more immediate and individual manner. This becomes obvious in their encounter with a boy called Frankie Foyle when they are teenagers. Sitting with him in his basement room, drinking and smoking, Ruby dares Frankie to kiss her. He hesitates initially, but then kisses her as Rose feels "sick from the booze, and the smoke, and the envy. [...] [She] wanted Frankie Foyle to kiss [her] too (116). He continues kissing Ruby even as

his fingers crept spiderlike onto [Rose's] shoulder and dropped down inside [her] blouse to find the nipple of [her] right breast. And even when his hand slid lower, traversing [her] flat stomach and thighs. And even when he shifted [her], because he wasn't quite comfortable, and even when he parted [her] long legs, Frankie kept kissing [Ruby]. And even when ... Even then. (116)

This brief sexual encounter results in a pregnancy for Rose, and while Ruby's physical connection to Rose means that she goes through some aspects of the

pregnancy as well, it is Rose who experiences the symptoms. Similarly, when Rose decides to give her baby up for adoption, she feels that she would “grieve, in a way Ruby could not, to lose this creature to whom [she] was mother” (158). Here, the physical reality of pregnancy and childbirth and the experience of motherhood are used to draw attention to the different ways in which Rose and Ruby respond to and inhabit their shared body.

Rose’s pregnancy works on another level as well, blurring the distinction between deviance and ‘normalcy’ more generally. Rose notes how “being pregnant did not feel normal. For the first time in [her] life, [she] felt fully freakish and monstrously, hideously, deformed” (156). As Rose points out, “It’s normal for me and Ruby to be who we are and live as we do” (ibid), but the pregnancy renders her ‘abnormal’. Her pregnancy joins her to another human being who is occupying her body, connected to her “by a spongy cord and natural law” (149). Rose must “surrender control of [her] body to the instincts of [her] unborn child and to the pain of labor and delivery” (163). Subverting social stereotypes that maintain that pregnancy is a natural and therefore ‘normal’ aspect of life, Rose shows that, for her, being conjoined to her sister is normal whereas the feeling of being joined to an unborn child is presented in terms of deviance and monstrosity.

These varying interpretations of the girls’ shared experiences problematize the very idea of a singular and essential truth of the body. Rather than offer a singular explanation, the novel points to the need to reconcile the girls’ personal narratives of their individual body with the plural social meanings that come to be associated with it. In fact, the very decision to use dual narrators in the novel points to the need to take seriously the process of negotiating various meanings and experiences and accepting that, as Rose explains, “There is conflict. There is compromise” (5). In this sense, because their shared body is inherently symbolic of negotiation and balance, conjoined twins are particularly powerful characters and narrators.

Indeed, the novel charts a certain trajectory towards the acceptance of multiple and rivalling interpretations. When Rose first sets out to write the story of her life, she decides to title it, “The Autobiography of a Conjoined Twin” (6), yet by the end of the novel she adopts “The Girls” as the title. Ironically, this is a label initially given to Rose and Ruby by others. Rose explains, “We’ve been called many

things: freaks, horrors, monsters, devils, witches, retards, wonders, marvels. To most, we're a curiosity. In small-town Leaford, where we live and work, we're just "The Girls" (3). She has spent the majority of the novel telling her story, trying to negotiate her life as Rose Darlen, not as one of 'the girls'. Ruby has done the same. At some point, however, their stories begin to intertwine and overlap. Ruby explains in her last entry that Rose is no longer calling the story "The Autobiography of a Conjoined Twin" because "the story is more than the title says, more than just the story of us" (339). Towards the end of the novel, Rose embraces the idea that the meaning of her identity—and of her life—is not just her own creation. Her life is the cumulative story of a negotiation of her own experiences and those of her twin as well as of the various meanings that society has attached to their shared body.

Rose mentions at the start of the novel that all of her relationships—not just the one she has with her sister—are delicate balancing acts. Thus, the observation of her own situation is equally applicable to the relationship between other seemingly disparate pairs. She says,

I thought my story's path would be a straight one. A simple one. After all, it is the true story of my life, to the point I have already lived it, and for which I know even the most incidental detail. But the story isn't straight. Or simple. And I see now, as I begin to think of the next chapter, that even the truth can spin out of control. My story. Ruby's story. The story of Aunt Lovey and Uncle Stash. The story of me, and we, and us, and them. The story of then. And the story of now. (47)

Conjoinment in this novel becomes a metaphor for compromise and a way to view contrasting ideas, not as distinct and polar opposites, but as positions along a broader spectrum. Viewed this way, conjoined twins are representative of negotiation. In their ability to highlight the fragile distinction between self and other; past and present; truth and fantasy; culture and biology; and other dichotomies, they become the literal and metaphorical 'enduring hyphenation' that Susan Peters introduced, and they are representative of the 'both/and' model that Chivers and Markotic advocate. As Susan Wendell states, "the distinction between the biological reality of a disability and the social construction of a disability cannot be made sharply, because the biological and the social are interactive in creating disability" (1996: 35). Lansens' representation of Rose and Ruby Darlen points to the myriad ways that the material of the body shapes

experience and is actively shaped by culture. If, as Elizabeth Grosz claims, "representations and cultural inscriptions quite literally constitute bodies and help produce them as such" (1994: x), then *The Girls* actively works to undermine notions of disability as either wholly biological or socially constructed.

‘Othering’ as Dynamic Process: *Cutting for Stone* by Abraham Verghese

Cutting for Stone (2010), by Abraham Verghese, takes up some of the issues raised in *The Girls*, including the various meanings of the body and its relation to subjectivity. However, Verghese, who is not only a novelist, but also a practising physician and Professor of Medical Theory and Practice at Stanford University, engages more explicitly with the medical construction of the body in particular. The novel tells the story of formerly conjoined twins, Marion and Shiva Stone, who are orphaned on the day of their birth when their Indian nun mother dies unexpectedly and their British surgeon father, who does not know about the pregnancy until their birth, abandons them. Told from the perspective of Marion Stone, fifty years after their birth, the novel takes place in different places—first in Addis Ababa, Ethiopia, a nation that is on the brink of revolution, then in New York City, where Marion is completing a medical residency program.

The narrative trajectory of the novel is unusual in that it reverses the stereotypical move from conjoinment towards separation. Instead of leading up to the point of separation, as was the case in several of the documentaries discussed earlier, *Cutting for Stone* opens with the cut. As their mother is dying on the operating table, unable to give birth to the boys and bleeding profusely, their father, Thomas Stone, must decide how to save her. While he is known as a levelheaded surgeon otherwise, his fear for the woman he loves makes him view the child (he does not yet know there are twins) as an enemy that he must expel from her body:

The enemy was more a foreign body, a cancer, than it was a fetus. No doubt the creature was dead. Yes, he would tap that skull, empty its contents, crush it just as if he were crushing a bladder stone, and then he'd pull out the deflated head which was the part that was hung up in the pelvis. If need be, he'd use scissors on its collarbones, scalpel on ribs; he would grab, slash, slit, and smash whatever fetal part obstructed delivery, because only

by getting *it* out could Mary be out of her misery and the bleeding cease.
(62; his emphasis)

In his haste to remove the ‘it’, Stone’s medical skills become a destructive force for the as yet unborn twins. Fortunately, Missing Hospital’s resident obstetrician, Hema, enters in time to save the babies from Stone’s injurious reaction. She is unable, however, to save their mother. When Hema finally removes the boys from Sister Mary’s body via caesarean, she discovers that they are conjoined via “a short, fleshy tube [that] passed from the crown of one to the other [...]. They were tethered together, but there was a fatal tear in this stalk, a jagged opening caused no doubt by Stone’s fishing with the basiotribe” (96). Because of the blood that is quickly pumping out of them via the tear in their joined flesh, Hema has no choice but to cut the boys apart to save their lives.

Afterward, Marion and Shiva are taken in and raised by Hema and her partner, Ghosh, who is also a doctor at Missing Hospital. The boys spend their lives as two people with individual bodies, but they share a connection that goes beyond the physical, and ultimately, at the end of the novel, it is another surgery that leads to their physical reunification. Years later, when Marion is completing his medical residency in the Bronx, he becomes gravely ill and needs a new liver to survive. It is Shiva who donates a lobe of his own liver to save his brother, but Shiva develops a bleed in his brain shortly after the surgery and unexpectedly loses consciousness. When he is declared brain-dead and taken off the ventilator, Marion lies next to him; he returns willingly to his origin—to the state of conjoinment in which he began life:

Ultimately it was the rude coldness of Shiva’s skin, the terrible separation it delineated of the living and the dead, the disarticulation of our bound flesh, that forced me to a new understanding, a new way of seeing us in the face of such rapid attrition, and this is what I came to: Shiva and I were one being—ShivaMarion. [...] *Shiva lives in me.* [...] *One being at birth, rudely separated, we are one again.* (518-519; his emphasis)

In this instant, Marion does not just understand himself as an extension of Shiva or half of the ‘whole’ that is ShivaMarion; he recognizes himself as Shiva. Marion reads their connection as permeating the physical boundary of the skin. In beginning with the separation and ending with this surgical reunification, the transplant of a section of Shiva’s liver into Marion, the narrative works backward,

complicating prevailing notions of subjectivity. Marion is, at the close of the novel, both self and other.

The novel also opens up debates about physical difference being a condition of the body or a product of society, thus engaging with the medical and social models of disability. In its detailed attention to the realities of the human body—health, sickness, pain, suffering, birth and death—the novel clearly appreciates the material reality of the body. Further, all of the main characters are medical practitioners, and the novel presents medicine as both a calling and a form of art. Sister Mary Joseph Praise is a nurse; Thomas Stone is a renal surgeon; Hema is an obstetrician; Ghosh is a general surgeon; Marion becomes a trauma surgeon; and Shiva becomes a famous fistula surgeon. Yet the role of medicine is both paradoxical and nuanced. As has been discussed, it is a medical decision that initially harms the twins and causes their separation, yet it is also what saves Marion and reunites the brothers who, after a lengthy separation, are brought together in New York City. In *The Girls*, medicine is portrayed as divisive, violent, and intrusive, but here, it is seen as a potentially healing force—and as a means to gain or re-establish a wholeness that has been lost. It is important to note that the initial cut is not done in a bid to ‘fix’ or ‘normalize’ MarionShiva, to simplistically impose social norms onto the body, but it is undertaken in a bid to save their lives. The view of medicine in this novel is therefore more sympathetic. Critics of the medical model of disability, as I mentioned earlier, assume that medicine imposes limiting social norms onto the physical landscape of the body, thus naturalizing them in the name of ‘normalcy’. Conjoined children, for instance, are separated because singletons are the ‘norm’, and conjoinment is considered a “socially challenging anatom(y)”, according to Dreger (2004: 10). *Cutting for Stone*, on the other hand, does not address the ‘broken bodies’ of conjoined twins, but instead demonstrates the potential healing power of medicine.

Moreover, health and well-being are shown to exist largely outside of socially determined categories of ‘normalcy’ and are more closely related to the individual experiences of the body. Shiva and Marion find safety and solidarity when they are together, even after their separation. They imitate their conjoinment on numerous occasions, and at no point is this choice viewed as a sign of sickness or deviance. Rather, the desire for conjoinment is associated with

a longing for wholeness as a preferred state of being. When the twins are babies, “no matter how far apart Hema put them, when she came to them again, they would be in a V, their heads touching, facing each other, just as they had been in the womb” (165). Even though they have been separated, they are still known from childhood, collectively, as ShivaMarion, because of their unusually close bond. According to Marion, “‘You’ or ‘Your’ never meant one of [them]” since an answer from one was always taken as an answer from both (189). In fact, it became so commonplace to accept an answer from one child that no one noticed when Shiva did not speak for long periods of time; Marion spoke for/as him.

Moreover, Marion says,

We—“The Twins”—were famous not just for dressing alike but for sprinting around at breakneck speed, but always in step, a four-legged being that knew only one way to get from A to B. When ShivaMarion was forced to walk, it was with arms locked around each other’s shoulders, not really a walk but a trot, champions of the three-legged race before we knew there was such a thing. Seated, we shared a seat, seeing no sense in occupying two. [...] Looking back, you could say we had some responsibility for people dealing with us as a collective. (ibid)

When Marion runs away from Hema to avoid punishment, he claims to “[feel] a vacuum where [his] brother should have been running next to [him]” and even as Marion starts to notice that he and Shiva are becoming distant in terms of their interests and personalities, there are moments when they re-enact their conjoinment with flawless precision (195). When, for example, the boys notice a couple running with a sick baby toward Mission Hospital, they

raced to meet them. The parents’ distress triggered this, gave us no time to debate our response, as a higher brain emerged, doing the deciding for us and guiding us to move as one organism if we knew what was best. I remember thinking, in the midst of that panic, how much I missed that state and how exhilarating it was to be ShivaMarion. (225)

As the brothers are growing up and growing apart, trying to find their own places in the world, they still revert back to their conjoinment; this is where they feel most complete. It is not uncommon for them, in the midst of uncertainty, for example, to sleep next to each other as young adults. Marion points out on one such occasion,

my greatest relief that night came when my head touched Shiva’s, a sense of safety and completion, a home at the end of the world. Thank God that whatever happened we’d always have ShivaMarion to fall back on, I

thought. [...] Together we had an unfair advantage on the rest of the world.
(246)

Marion recognizes the strength of their bond and simulates their conjoinment during times of difficulty. At one point, he discovers that Shiva has been intimate with Genet, the girl he plans to marry. He decides, "If there were filaments and cords of yolk or flesh that kept our divided egg sticking together, I was taking a scalpel to them" (332), but even though he tries to remain distant from Shiva over a number of years, cutting himself psychically from his brother, he returns to him on several occasions; the imaginary scalpel that he invokes to sever their bond is of no use. As their adoptive father, Ghosh, is dying from leukemia, both boys keep vigil outside of his door. Marion convinces Shiva to join him in the bed they once shared. Even though they "slept awkwardly, on the edges of the mattress, getting up several times in the night to check on Ghosh, [Marion explains how] by morning, [their] heads were touching" (352). Here, the brothers revert once again to their state of conjoinment. And finally, when Marion is forced to leave Ethiopia because of his supposed connection to anti-establishment rebels, he admits to feeling incomplete. Holding Shiva for the last time, he says, "I'd forgotten what it felt like to hold him, what a perfect fit his body was to mine, two halves of a single being" (363). Marion considers Shiva an integral part of himself, despite the fact that their physical connection was severed at birth. While he claims that he is unable to forgive Shiva for having sex with Genet, he cannot escape their connection, which may originate in the material physical connection that united them at birth, but extends far beyond this initial connection.

In pointing to this physical and spiritual connection between the brothers, the novel raises awareness of psychosomatic experiences that cannot easily be explained within a limited scientific framework and might therefore easily be overlooked by some medical practitioners. Conjoinment is once again used to demonstrate this point. Marion is not visibly physically different, and there is no obvious mark of his former conjoinment, but his body takes on two different meanings: first, he continues to perceive himself as a conjoined twin though the world does not read him as such. He has been separated from Shiva, and he exists as a single-bodied individual, yet there are two bodies that he occupies simultaneously: MarionShiva and Marion. The medical cut does not 'solve' the

'problem' of conjoinment, which is shown to affect his sense of identity on a spiritual rather than just physical level. Indeed, his former conjoinment haunts Marion throughout his life and determines the trajectories of his character development and narrative, which always involve questions of similarity/difference, togetherness/separation, and proximity/distance. In this sense, the novel raises awareness of the fact that separation surgery and other forms of medical intervention need to consider more carefully the inner life of the subject and develop a more nuanced understanding of the patient's experience of the individual body.

The novel also draws on the individual experience of the body to point to the contingency of social norms. Specifically, it illustrates how categories of 'normalcy' are open to negotiation rather than being simple physical truths and raises awareness of the fact that the social norms applied to the body are often arbitrary. Marion and Shiva have been separated, but Marion does not experience positively his 'normal' body. Instead, he questions throughout his life whether the initial cut is the reason for the problems he encounters. He bemoans the fact that he did not have a choice to live conjoined to his brother. He wonders,

What would it have been like if ShivaMarion walked around with heads fused, or—imagine this—sharing one trunk with two necks? Would I have wanted to make my way—our way—through the world in that fashion? Or would I have wanted doctors to try and separate us at all costs?

But no one had given us that choice. They'd separated us, sliced through the stalk that made us one. Who's to say that Shiva's being so different, his circumscribed, self-contained inner world that asked nothing of others, didn't come from that separation, or that my restlessness, my sense of being incomplete, didn't originate in that moment? And in the end, we were still one, bound to each other whether we liked it or not. (274)

Here, Marion describes two men with two distinct personalities, but he views each individual difference as that which is lacking in the other twin. In other words, he thinks about the state of conjoinment in terms of wholeness and argues that the characteristics that now set him apart from his brother once made up a single personality that was divided at birth. In this sense, the idea that separation surgery will necessarily have a positive impact on the way in which conjoined twins experience their body and subjectivity is challenged.

Cutting for Stone also incorporates certain insights associated with the social model of disability by pointing to the shared communal experience

resulting from physical difference and other forms of social stigmatization. Marion and Shiva, through the initial cut that separated them, are afforded the opportunity to live 'normal' lives, but even as adults, they actively connect with 'othered' groups of people. Marion goes to New York City, specifically the Bronx, where he completes a surgical residency at Our Lady of Perpetual Succour, a hospital that treats society's poorest. A fellow resident explains how their hospital was admired at one time but "went the way of the neighborhood: it became poor in catering to the poor" (390). According to him, "[t]he poorest in America are the sickest. Poor people can't afford preventive care or insurance. The poor don't see doctors. They show up at our doorstep when things are advanced" (ibid). Marion thus dedicates his time and talent to treating those who have advanced conditions because of their poverty or trying to save those who come to the hospital because of the traumatic injuries they have earned on the streets. Thousands of miles away in Addis Ababa, Shiva assumes a similar role, although in a different area of medicine, treating women who suffer from vaginal fistulas. While he does not complete any formal medical training, he studies under Hema and eventually becomes "the world's expert and the leading advocate for women with vaginal fistulas" (467). While generally devoid of emotion throughout his life (Marion often states that Shiva is governed by reason), Shiva cares for women who have been abandoned by their families and spouses, acknowledging their dire circumstances and treating them as human beings rather than bodies in need of repair. In fact, Shiva seems to have a profound understanding of them that others do not. Even though Marion and Shiva are not conjoined, their connection with underprivileged and marginalized people can be read as an outcome of their potential otherness, the fact that they might have been conjoined. Here, *potential* physical difference facilitates empathy toward outsiders *and* an interest in medicine, so that concerns with social processes of 'normalcy' and victimization and an interest in medical practice come to condition each other.

The text also shows how these categories of difference affect the health and wellbeing of the human body due to varying standards of medical care. At Missing Hospital in Ethiopia, the medical staff gets by on the bare minimum in terms of medical supplies and equipment, and even in the United States, there is a deep gulf between Our Lady of Perpetual Succour in the Bronx where Marion practices, and

Mecca, the wealthy Boston hospital where his biological father, Thomas Stone, operates. An analogy provided by one of the other residents reveals the 'truth' about the vast difference between the two types of hospitals:

[Ellis Island Hospitals] are always in places where the poor live. The neighborhood is dangerous. Typically such hospitals are *not* part of a medical school. Now take this saltshaker. That is a Mayflower hospital, a flagship hospital, the teaching hospital for a big medical school. All the medical students and interns are in super white coats with badges that say SUPER MAYFLOWER DOCTOR. Even if they take care of the poor, it's honorable, like being in the Peace Corps, you know? (401; his emphasis)

He goes on to explain how doctors, residents, and interns in 'Ellis Island Hospitals' are foreign; "some are all Indian. Some have more of a Persian flavor. Others are all Pakistani or all Filipino" (ibid), while those who practice in 'Mayflower Hospitals' are mostly American medical students and practitioners. This highlights the fact that race, ethnicity and socioeconomic factors are conditions of otherness that directly influence the medical training and care the individual receives. Thus, the novel draws attention to the way in which medical treatment and, by extension, the individual's health and wellbeing depend on specific social and cultural factors.

Cutting for Stone, in the way that it tackles both the material reality of the body as well as its position as a socially constructed entity, offers a nuanced understanding of physical difference that challenges both the medical and the social models of disability. Importantly, conjoinment is neither presented as a purely medical condition associated with the body nor is physical difference entirely socially imposed. The emphasis throughout the text lies on the individual's own experience and negotiation of the physical realities and social meanings of the body. Thus, for instance, Marion is not victimized through a physical condition, but rather *chooses* conjoinment as a means of describing his identity and narrating his life story. In a sense, then, an imagined disabled or non-normative body is not a sign of failure, but presented as another form of existing in the world and understanding the self. This helps to produce a more nuanced understanding of the social model with its tendency to rely on the concept of victimization. In Verghese's novel, the category of the 'other' can take on an empowering and enabling role: Marion is not 'othered' by society because of his

separation, but he 'others' himself by reading himself as conjoined throughout his life.

At the same time, the body is not denied, even though the very distinction between an essentialist and constructionist reading of the body is rendered problematic. Marion continues to long for Shiva because he was 'born' conjoined, which may imply an essentialist, biologically determined connection between the two brothers. However, it is also possible to argue that Marion actively constructs himself as a conjoined twin through his reading and medical learning. As a result, it is impossible to decide whether his longing for his brother is biologically determined or a result of Marion's own construction of his identity and life story. Ultimately, the novel does not dissolve this tension and therefore, once again, points to the significance of acknowledging the individual's own negotiation of his body and its meaning.

Overall, Verghese's text shows that for medicine to be healing and to fulfil its potential, it needs to embrace lessons from the social model, challenging our understanding of 'normalcy' and its equation with health; questioning medicine's role in facilitating health; and taking seriously the forces of 'othering' and marginalization and their impact on medical practice. This, once again, recalls Susan Peters' notion of the 'enduring hyphenation': it is necessary to examine the bodily realities and medical possibilities as well as the social dynamics of 'othering' and imposition of norms. *Cutting for Stone* uses conjoinment to bring together the medical and the social in this way.

Ultimately, then, the text moves beyond binary understandings of medical versus social figurations of the body. The body is not just a construct, but also a physical reality; at the same time, medicine—to be a positive and healing force—needs to be aware of the ways in which social norms impact medical practice. The novel also undoes the binaries of body versus mind that often feed into the medical and social model and maintains that healing involves both mind and body. Towards the end of the novel, Marion hears his father speak to a large audience of medical students at Mecca Hospital. In his speech, Thomas Stone alludes to a psychosomatic approach to healing when he relays a letter that was written by the mother of a deceased patient who was treated at his hospital by his team:

'Dr. Stone—My son's terrible death is not something I will ever get over, but perhaps in time it will be less painful. But I cannot get over one image, a last image that could have been different. Before I was asked to leave the room in a very rough manner, I must tell you that I saw my son was terrified and there was no one who addressed his fear. The only person who tried was a nurse. She held my son's hand and said, "Don't worry, it will be all right." Everyone else ignored him. Sure, the doctors were busy with his body. It would have been merciful if he had been unconscious. They had important things to do. They cared only about his chest and his belly. Not about the little boy who was in fear. Yes, he was a man, but at such a vulnerable moment, he was reduced to a little boy. I saw no sign of the slightest bit of human kindness. My son and I were irritants. Your team would have preferred for me to be gone and for him to be quiet. Eventually they got their wish. Dr. Stone, as head of surgery, perhaps as a parent yourself, do you not feel some obligation to have your staff comfort the patient? Would the patient not be better off with less anxiety, less fright? My son's last conscious memory will be of people ignoring him. My last memory of him will be of my little boy, watching in terror as his mother is escorted out of the room. It is the graven image I will carry to my own deathbed. The fact that people were attentive to his body does not compensate for their ignoring his being.' (423)

After reading the letter, he asks, "'What treatment in an emergency is administered by ear?'" (424). Marion, having read Stone's textbook many times, responds, " 'Words of comfort'" (425). This letter and the response to Stone's question highlight the importance of treating a patient not merely as a body, but as a multi-faceted being. Overall, *Cutting for Stone* draws on conjoinment to champion an understanding of physical difference that incorporates insights derived from both the medical and social models and places great emphasis on the individual's own negotiation of the two.

This is a model that Verghese promotes in his own practical and theoretical work as a doctor and professor. According to his own website, Verghese was the founding director of the Center for Medical Humanities & Ethics at the University of Texas Health Science Center in San Antonio,

[where] he brought the deep-seated empathy for patient suffering that had been honed by his previous experiences to his new role in the medical humanities. He gave the new Center a guiding mission, "Imagining the Patient's Experience," to emphasize the importance of truly caring for the patient. He saw empathy as a way to preserve the innate empathy and sensitivity that brings students to medical school but which the rigors of their training frequently suppress. ("Abraham Verghese")

His interests in bedside manner, the connection between the patient and the physician, as well as the connection between body and mind, are manifest in *Cutting for Stone*. The fact that Verghese chose to draw on the figure of conjoined twins in his novel once again reinforces the idea that representations of conjoinment offer important means of thinking critically about topical concerns. These include understandings of the body and subjectivity more generally, but also, in this particular case, important questions pertaining to health, wellbeing and medical practice.

Chapter 5: Temporal Entanglement: Conjoinment, Sexuality & Identity Formation

In *Twins in Contemporary Literature and Culture* (2005), Juliana de Nooy examines the myriad narrative uses of (mainly identical) separate twins, pointing to the ways in which storytellers use them as “sites of contestation” (164)—as the “entry points” (xiv) into current preoccupations. As open sites, according to de Nooy, their “meaning is not fixed, is always ‘up for grabs’ to a large extent” (64). A similar case can be made for conjoined twins, as contemporary writers often appropriate conjoinment to explore different aspects of human life, specifically with regard to the body and subjectivity. The previous chapter explored how contemporary fiction draws on the figure of conjoined twins to think beyond the medical and social models of disability in a bid to develop a more nuanced understanding of physical difference. This chapter does not abandon the questions raised in previous chapters concerning subjectivity and the body, but shifts the emphasis of discussion towards a more explicit examination of sexuality.

Intersections: Crip Theory

In *Crip Theory: Cultural Signs of Queerness and Disability* (2006), Robert McRuer examines the ways in which both corporeal (disabled) and sexual (queer) normativity and marginality are produced and upheld—and how those categories might be rewritten and consequently unsettled. His theory is particularly relevant at this point in the thesis, since this chapter turns to questions of sexual dissidence. McRuer asserts, “the system of compulsory able-bodiedness, which in a sense produces disability, is thoroughly interwoven with the system of compulsory heterosexuality that produces queerness: [...] compulsory heterosexuality is contingent on compulsory able-bodiedness, and vice versa” (2). Specifically, this chapter expands on an area of discussion that has already been mentioned in previous chapters, namely, the fact that the sexual lives of conjoined twins have attracted considerable attention and have played a prominent role in representations of conjoinment at least since the rise of freak show culture in the nineteenth century. The sustained interest in conjoinment and sexuality that runs through many of the novels written about conjoined twins in the past ten years is

part of a longer history of representation, particularly post-1960s fiction, which explores sexual experience. What becomes more noticeable in twenty-first century representations, however, is the use of conjoinment to deal with the topics of sexual dissidence and sexual and gender identity formation.

McRuer uses ‘crip’—a term historically infused with negativity—to point to the arbitrariness of able-bodiedness as a category of ‘normalcy’, much like ‘queer’ has been used to the same end for heteronormativity. For McRuer, able-bodiedness and heterosexuality are categories of invisibility precisely because of their status as non-identities, or “as the natural order of things” (1), while homosexuality and disability are spectacles—highly visible because of their placement as oppositional categories of identity. Lennard Davis makes a similar claim in *Enforcing Normalcy* (1995), stating “The hegemony of normalcy is, like other hegemonic practices, so effective because of its invisibility. Normalcy is the degree zero of modern existence” (170). Because, as McRuer rightly asserts, the systems of compulsory heterosexuality and able-bodiedness “depend on a queer/disabled existence that can never quite be contained, able-bodied heterosexuality’s hegemony is always in danger of collapse” (2006: 31). It is therefore possible to imagine that

crip theory (in productive conversations with a range of disabled /queer movements) can continuously invoke, in order to further the crisis, the inadequate resolutions that compulsory heterosexuality and compulsory able-bodiedness offer us. And in contrast to an able-bodied culture that holds out the promise of a substantive (but paradoxically always elusive) ideal, crip theory would resist delimiting the kinds of bodies and abilities that are acceptable or that will bring about change. (ibid)

McRuer makes clear the fact that his agenda of ‘cripping’ is not meant to “deny the materiality of queer/disabled bodies” (ibid)—a caveat that echoes contemporary debates about the social construction of the body which I discussed extensively in the introductory chapter—but rather to interrogate “the substantive, material uses to which queer/disabled existence has been put by a system of compulsory able-bodiedness, about insisting that such a system is never as good as it gets, and about imagining bodies and desires otherwise” (32).

To consider further the relation between disability and sexuality, this chapter draws specifically on recent critical work in the fields of queer theory and

sexuality studies, which has raised increased awareness of the intimate relationship between time and sexuality. This work has shown that normative figurations of time, primarily linearity, teleology and futurity, contribute to the naturalization of certain forms of sexuality. Because the same normative understandings of time figure prominently in representations of the life course of conjoined twins, as has been discussed previously, the focus on temporality allows for a nuanced understanding of how conjoinment relates to sexuality. It perhaps comes as no surprise that McRuer is currently working on his next book, tentatively titled, *Crip Time*, as there is no denying the relation between time, sexuality, and disability—a relation that is particularly pertinent to the discussion of fictional writing on conjoined twins. Fictional narratives offer a variety of possibilities to manipulate time, thereby exposing the temporal norms that otherwise structure the individual's life course. As articulated by Valerie Rohy in *Anachronism and Its Other: Sexuality, Race, Temporality* (2009), “the artificial temporality of narrative form alerts us to the fictional dimension of chronology as such: after all, time is a trope” (xiv). This is in contrast to the documentaries I discussed earlier, which do not themselves expose or acknowledge how normative understandings of time structure their narratives of conjoined twins' lives even though they implicitly rely on the same regulating force of linear temporality. The two novels examined in this chapter, *First Person Plural* (2007) by Andrew Beierle and *Half Life* (2007) by Shelley Jackson, share an interest in the connection between normative time lines, conjoinment and dissident sexuality. Beierle reads conjoinment in relation to homosexuality whereas Shelley explores the similarities between conjoinment and transgenderism. Although the two novels are radically different, in both cases, conjoinment serves to trouble the normative temporality of sexual and gender identity formation.

Linearity and Futurity

In the past decade, the relationship between sexuality and time has attracted considerable critical attention. These various theorizations have, at times, been recuperated under the umbrella term ‘queer time’, for instance, in Judith Halberstam's 2005 monograph *In a Queer Time and Place: Transgender Bodies, Subcultural Lives*, and in the 2007 *GLQ* special edition, edited by Elizabeth

Freeman. However, in a roundtable discussion published in the very same issue entitled “Theorizing Queer Temporalities”, Annamarie Jagose warns that ‘queer time’ is simply too unstable to be useful as a term. In its representation of a myriad debates, the “adjectival ‘queer’ [throws] a proprietary loop around properties or characteristics that have long been theorized as at the heart of ‘time’ or, for that matter, ‘history’” (Dinshaw, Edelman, et. al: 186). Carla Freccero echoes her concern by asking, “what the specificity is of ‘queer’ in relation to temporality, since [she] agree[s] that not all nonlinear chronological imaginings can be recuperated as queer” (ibid: 187). Taking into account Jagose and Freccero’s caveat, it is important to acknowledge that the term ‘queer time’ has some potential to present more problems than it solves.

It is therefore necessary to ask what non-normative aspects of time critics are referring to when they speak about ‘queer time’ and what the specific relations between these non-normative time lines and sexuality are. Halberstam, for instance, is particularly concerned with the normative figuration of the individual’s life course, therefore arguing that queer time is “about the potentiality of a life unscripted by the conventions of family, inheritance, and child rearing” (2005: 2). For her, ‘queer time’ is defined against a normative life course, which includes certain “paradigmatic markers of life experience—namely, birth, marriage, reproduction, and death” (ibid.). In *Time Binds: Queer Temporalities, Queer Histories* (2010), Elizabeth Freeman also challenges the normative “novelistic framework” (4) of what it means to “have a life at all” (ibid) in a society where

properly temporalized bodies [are linked] to narratives of movement and change. These are teleological schemes of events or strategies for living such as marriage, accumulation of health and wealth for the future, reproduction, childrearing, and death and its attendant rituals. (ibid)

For Freeman, individual bodies are bound by time in a normatively structured life course marked by “[a series of] cause and effect: the past seems useless unless it predicts and becomes material for a future” (5). Freeman refers to this phenomenon as “chrononormativity”, the process through which the construction of time is made to appear natural, creating a social structure within which individual and collective subjectivities take shape (3). Both Halberstam and

Freeman equate a normative life course with a time line that is characteristically linear, teleological and future-oriented, or “straight” according to anthropologist Tom Boellstorff (2007: 228). Following Boellstorff, Rohy defines ‘straight time’ as “regular, linear, and unidirectional” (2009: xiv).

This chapter is primarily concerned with the way in which the modalities of straight time regulate the individual life course, facilitating the naturalization of normative ideas of gender and sexuality, which are as follows: a child is born as either male or female and, in accordance with his or her sex, develops a single and stable gender identity early on in childhood; sexual attraction to the opposite sex is manifested during adolescence; marriage confirms sexuality and offers a socially sanctioned environment in which to reproduce. In this formulation, heterosexuality is, as Angus Gordon has argued in his essay “Turning Back: Adolescence, Narrative, and Queer Theory” (1999), “installed in advance as the default sexual orientation, the standard denouement” towards which the individual life course moves (6). The history of this prescriptive narrative of individual sexual development is outlined by Freeman, who points out that Freud, in the early twentieth century, “introduced key temporal concepts to explain [...] the progress to normative heterosexuality” (161) and “[insisted] that sexuality develops in a linear fashion towards heterosexual reproduction” (161-2).

As has already been discussed briefly in chapter two, the ideological link between heterosexuality and reproduction finds expression in the normative force of futurity or ‘reproductive futurity’, as Lee Edelman calls it. Edelman fully rejects the “absolute privilege of heteronormativity”, arguing instead for “a queer resistance to this organizing principle of communal relations” (2004: 2). He denies the social fantasy of reproductive futurity and consequently the view of “history as linear narrative (the poor man’s teleology) in which meaning succeeds in revealing itself—*as itself*—through time” (ibid; his emphasis). He objects to the Child as a symbol of the privileging of futurity, which is inextricably linked to heterosexuality. In a later article, “Ever After: History, Negativity, and the Social” (2007), Edelman discusses the ‘after’ of sex, which automatically implies a connection between linearity, reproduction, and heterosexuality. It is the ‘after’, achieved by heterosexuality or “heterogenital coupling” (470), that is “socially valorized” (ibid), while “nonreproductive sexualities” (ibid) are the “embodiment

of the antisocial” (ibid). Straight sex becomes “the agent of historical continuity”—or the means through which the normative life course can continue—because only the redemptive act of straight sex can confirm a future (ibid).

Such varied attempts to rethink ‘straight time’ raise the question of how one can conceive of alternate constructions of time. As part of his critique of reproductive futurity, Edelman encourages queers to say ‘no’ to the future and embrace the unravelling of straight time even if (or precisely because) this entails the negation of a stable identity. Halberstam is also interested in critiquing ‘straight time’, but hesitates to offer a single conclusion, as her ‘queer time’ should be understood in more open-ended terms as “a critique of the careful social scripts that usher [...] us through major markers of individual development and into normativity” (Dinshaw, Edelman, et. al: 182). Boellstorff proposes “coincidental time” (2007: 240) as “one of many possible examples of alternate temporalities that could be used to destabilize straight time — to queer it, in fact” (ibid). This strategy of moving away from ‘straight time’ “[represents] a truly radical queering of time. [...] It would be a time in which dragging, lagging, futurism, nostalgia, and a host of other temporally inflected categories would be fundamentally reconfigured” (ibid: 241). In this design, time becomes cyclical and overlapping, thus contrary to normative linear time. Even Boellstorff realizes the impracticality of his proposal, suggesting that a move away from ‘straight time’ may not even be possible, at least not within a Western temporal framework. This outlook resonates with Freeman, who suggests that chrononormativity is not a process that we can get beyond so much as one that can be disturbed enough for its supposed naturalness to become open to critical interrogation. Rather than hope to step outside of straight time, she suggests—through close readings of several texts—that temporal figurations such as haunting, reverie, anachronism, the “antirepresentational privileging of delay, detour, and deferral” (2010: 64), and “erotohistoriography” (ibid: xvi) can exert “a necessary pressure on the present tense” (ibid: 64) by placing it “into [a] meaningful and transformative relation with [the past]” (ibid: 95). Many of these uses of time appear in narrative strategies employed in novels dealing with conjoined twins, as I will go on to demonstrate, which raises the question of how to think about the relation between conjoinment, sexuality and time.

Non-linearity, Identity & Conjoined Twins

Following a normative time line involves the movement towards the establishment of a single, legible identity—sexual and otherwise. Conjoined twins pose a threat to such narratives of identity formation that unfold in a linear and teleological fashion. The trope of the ‘cut’ can help to bring together the relationship between time, sexuality and conjoinment. In Aristophanes’ myth of origin speech in Plato’s *Symposium* (1994), for instance, the ‘cut’ plays a central role in constituting simultaneously the individual subject and desire. According to this myth of origins, each person existed as a round, complete circle with “four hands and the same number of legs, and two absolutely identical faces on a cylindrical neck. They had a single head for their two faces (which were on opposite sides), four ears, [and] two sets of genitals” (ibid: 25). When Zeus decided to weaken these hermaphroditic creatures by cutting each whole into two halves—a punishment that would render them unable to function to their greatest potential—desire was immediately born out of the sudden lack that each human half felt. This cut caused them to “throw their arms around each other in an embrace and [long] to be grafted together” (ibid: 27). Aristophanes speculates that their despair and subsequent refusal to do anything without their other halves meant that “they died of starvation and general apathy” (ibid). If one half of a pair died, the “survivor went in search of another survivor to embrace” (ibid). This desire for wholeness, as Aristophanes explains, is why humans feel desire and are always searching for their other halves.

Responding to the impending death of humanity, Zeus re-positioned the creatures’ genitals in such a way that would ultimately lead to procreation between opposite sexes. Joining together again, even if temporarily, would result in a new way of producing offspring for the man-woman creatures and in addition, would allow them—as well as same-sex creatures—to become whole again through a temporary union with their lost other halves. For Aristophanes, then, conjoinment is the origin as well as the aim of human development; desire is constituted by a lack that results from the separation, the ‘cut’, and is fulfilled as soon as conjoinment takes place through temporary sexual union.

Aristophanes' speech can help to understand some of the paradoxes that underwrite the eroticization of conjoinment. The last part of Aristophanes' speech is particularly relevant to an examination of conjoined twins, who, according to this myth, should not experience desire. As the 'whole' that Aristophanes describes, they do not suffer the same lack that other human halves would experience; there is therefore no need to search beyond themselves, as they are always already complete. In fact, Aristophanes hypothesizes that the human halves he described—those that resulted from the 'cut'—would actually choose to be conjoined if given the chance:

Imagine that Hephaestus came with his tools and stood over them as they were lying together, and asked, "What is it that you humans want from each other?" And when they were unable to reply, suppose he asked instead, "Do you want to be so thoroughly together that you're never at any time apart?" If that's what you want, I'd be glad to weld you together, to fuse you into a single person, instead of being two separate people, so that during your lifetime as a single person the two of you share a single life, and then, when you die, you die as a single person [...]. It's obvious that none of them would refuse this offer; we'd find them all accepting it. (ibid)

Positing blissful conjoinment as the imagined alternative to all human strife, Aristophanes reverses contemporary constructions of identity formation, which anticipate the 'cut' as the goal of the conjoined twins' development, the only means through which conjoined twins can become single and self-contained. These narratives often view surgical separation as the first step towards building a 'normal' life, which involves finding a romantic partner and possibly starting a family. Ironically, then, the cut constitutes the conjoined twins' identity as a 'whole' human being, precisely because of the lack it produces, which in turn enables the twin to establish a 'clear-cut' sexual identity.

In terms of inspiring desire, the situation offers some irony: within Aristophanes' framework, conjoined twins should not be appealing because they already exist as one with their ideal complement. Yet, in the popular imagination, conjoined twins have undoubtedly become the object of erotic fascination and attraction, as has been discussed earlier, for instance, with regard to the Hilton sisters, Daisy and Violet. Conjoined twins appear attractive because they hold out the promise of an elusive wholeness that is eroticized precisely because it is viewed as the outcome of all erotic desire: the ultimate goal of seeking reunion

with one's complementary other. Threatening the borders of self and other and promising the undoing of the self, conjoinment can be explained in terms of *jouissance*, which Julia Kristeva, in her work on abjection, describes as the eroticized experience of the self's dissolution and merging with an other. It "alone causes the abject to exist as such. One does not know it, one does not desire it, one joys in it (*on en jouit*)" (1982: 9; her emphasis). At the same time, paradoxically, the appeal of conjoined twins may also be the consequence of wanting to insert oneself into an existing whole—to split the conjoined 'couple' so that desire is transferred from the twin 'couple' to the desiring self. David Halperin examines the etymology of the word, 'sex', which "may derive from the Latin *secare*, "to cut or divide" (2002: 137). In this sense, the sexualization of conjoined twins always anticipates the 'cut'. Inserting oneself into the whole and splitting it apart by attracting desire confirms the self against the 'other'; it reasserts an identity that conjoined twins threaten, facilitating an erotics of the 'cut' based on subordination and the affirmation of the self rather than its undoing.

The dualities of wholeness and lack and the different erotics they give rise to also have different temporal implications. Attached to one another, conjoined twins appear outside of the time lines that govern the human and sexual subject: their autonomy excludes them from the struggle towards reunion that marks the linear, teleological and reproductive time line on which singletons experience their sexuality.³⁵ The erotics of *jouissance* that the figure of the conjoined twin can inspire may hold a queer temporal potential; Edelman, for instance, defines *jouissance* in temporal terms as that which "defines and negates us" (2004: 5) through a process of "embracing the ascription of negativity to the queer" (ibid: 4) rather than "reproduc[ing] the constraining mandates of futurism" (ibid). At the same time as the eroticized figure of the conjoined twin troubles normative time lines, it is also deeply implicated in them due to the erotics of the 'cut'. Conjoinment, like sexual identity formation, is normatively driven towards the moment in which the 'cut' takes place and an identity is clearly established. The 'cut' represents the moment of identity formation, literally when twins are divided

³⁵ Importantly, for Plato, reproductive time is *not* exclusively heterosexual. Quite the contrary, he makes room for same-sex desire and, indeed, later on in the *Symposium* privileges relations that can produce 'mental' children (beautiful and eternal ideas) rather than mere 'physical' ones, which cannot transcend the material and temporal sphere.

and singletons are created, and figuratively when a distinct and clearly legible sexual identity is created.

From Plato to Kristeva and beyond, therefore, we have come to understand sexuality and desire in terms of difference and wholeness. In writing about conjoined twins, contemporary authors find the means to offer a fresh perspective on these dynamics of desire and connect them to contemporary debates. The two novels that I discuss here represent and play with normative structures of time, showing that conjoined twins are both inside and outside the normative time lines that govern identity formation and sexual experience. In *First Person Plural*, Beierle explores a life that is much more complicated and does not lend itself to a straightforward narrative. Because of that, he exploits the limitations of normative time and opens up possibilities for alternative readings of queer and straight time. Jackson's *Half Life* employs a variety of narrative techniques that disrupt normative figurations of time and lead to a temporal entanglement that reflects the physical entanglement of conjoinment.

Out of Time: *First Person Plural*

The representation of conjoined twins in *First Person Plural* problematizes the perceived distinction between straight and queer time. It challenges the association of queer time with non-normative sexuality (in this case homosexuality) and straight time with normative heterosexuality. The first step in this process is to show how a homosexual subject can expose normative time (straight, linear, unidirectional, and usually used to characterize heteronormativity) as a construct rather than a naturally given phenomenon. The second step is to reveal how normative time is not an exclusive characteristic of heteronormativity, but one that is also associated with homonormativity.

Owen and porter Jamison, as they are commonly referred to as children, are dicephalus conjoined twins born to educated and financially secure parents who chose not to separate them because of the medical risks. The story's narrator, Owen, makes clear that he and his brother were brought up as individuals despite their shared body and were always encouraged to pursue their own interests. They were not kept from the world, but were instead prepared to live in it. That they were featured in popular magazines and documentaries as children and

young adults meant that “people [thought] they knew [them], and that [...] engendered respect, even admiration” (4). The boys thrived together as children and learned that they had to work to establish themselves as individuals.

The delicate balance of ‘give and take’ that they create, which works throughout their childhoods, becomes complicated when Owen realizes that he is gay at age 15. Prior to this, the twins’ sexuality was expressed through masturbation, a shared activity that unified them. Owen and Porter “enjoyed sex together, in its purest form, simultaneously, driven only by the imperative of the experience itself and not yet by the desire for another person”, but once Porter begins to direct his sexual desire toward women, Owen senses a difference between them (18). This difference becomes even more profound as they get older, and Owen regards being gay as the elemental attribute that distinguishes him from Porter. The process of claiming this (sexual) identity allows him to be psychically ‘cut’ from Porter even though they are physically one. In fact, when Owen experiences desire for a man for the first time, manifested by the erection that he obviously cannot hide from the twin with whom he shares his penis, he claims that he can “feel [Porter] pulling away, as if [their] separation, arrested *in utero* some sixteen years before, had begun anew” (23, his emphasis). From his adult perspective in the present, Owen is looking back upon the formation of his identity as a gay man, trying to make sense of what is happening now, in the present tense. He sees this moment, during which he understands his center of sexual desire as different from Porter’s, as the moment when they are, symbolically, cut apart. In this sense, sexual identity formation coincides with and, indeed, facilitates the establishment of an increasingly autonomous sense of self for Owen.

It is at this point that the twins’ disparate sexual identities begin to intrude upon the linear structure of the novel and impede the normative process of growing up that Kathryn Bond Stockton describes in *The Queer Child: Or Growing Sideways in the Twentieth Century* (2009). According to her, the process of ‘growing up’ uses a metaphor of “gradual growth, [a] suggested slow unfolding, which, unhelpfully, has been relentlessly figured as vertical movement upward (hence, ‘growing up’) toward full stature, marriage, work, reproduction, and loss of childishness” (4). She describes a model of normative time that is vertical, and

she seeks to “prick (deflate, or just delay)” (11) that model by examining the queer child as that which “spreads sideways—or sideways and backwards” (4). This idea is particularly useful as a way of analyzing Porter and Owen’s circumstances. Whilst masturbatory sex united them during childhood, the boys moved together within a normative framework of growing up. Because there was nothing to counter their movement upward or forward, the linear narrative structure could easily accommodate their story. Despite the fact that they have different interests and personalities, there is at this point little expectation that they will not follow the same heteronormative path. In fact, the “extraordinarily handsome young men” (9) with the “faces of angels— and a heavenly body” (ibid) had been raised to believe (somewhat idealistically) that they could achieve all of the paradigmatic heteronormative markers of growing up that their mother dreamed of: “a steady girlfriend, an engagement, [and] a wedding” for each of them (84). However, as soon as Owen begins to claim his sexual identity, his trajectory deviates from his brother’s, and the linear, chronological arrangement of the narrative is unable to contain the two stories simultaneously. The character of Owen therefore becomes the method through which Beierle ‘queers’ the straight time of his narrative; the process of ‘coming out’—told in a series of vignettes—punctuates the unidirectional, forward (or ‘upward’, to borrow Stockton’s terminology) path of Porter’s story; each time Owen reveals his sexuality to someone else, Porter’s life story must accommodate this ‘sideways’ deviation.

That the two main characters in *First Person Plural* are conjoined is a symbolic expression of the difficulties of imposing a normative time line on a life. On the one hand, the narrative is restricted by the linear chronology of conventional markers of ‘normalcy’ that Porter’s life imposes on the overall framework of the novel. On the other hand, Beierle expands the narrative structure to accommodate Owen’s story, revealing the potential permeability of normative time. Beierle problematizes the limitations of a linear narrative form because he has a gay conjoined twin who ‘leaks’ (literally and figuratively) out of the boundaries imposed by the structure he adopts for the other, straight conjoined twin. As a heterosexual male, Porter’s life exists neatly along an undisturbed, single trajectory, and the narrative structure attempts to adhere to

that story, but paradoxically, Owen's life and therefore his story do not fit neatly into that design once he understands his sexual difference.

It may initially appear that *First Person Plural* presents a typical coming-out story, defined by Gordon as "involv[ing] a retrospective exegesis from the perspective of the 'out' adult gay or lesbian subject, in which virtually every aspect of his or her adolescent life can be understood in terms of its relation to the eventual realization of homosexual identity" (1999: 1). In this sense, Owen's story—presented retrospectively—would not be much different from Porter's in its narrative structure, running in a linear and teleological fashion along its homonormative trajectory towards the moment of self-realization and coming out. However, Beierle's text is more ambiguous: at the same time as he builds his story of one twin's struggle for identity, he also 'cuts it open' to accommodate the story of the other. Rather than presenting two parallel time lines, one heteronormative and the other homonormative, Beierle draws on the figure of the conjoined twin to present a more complex form of temporal entanglement that disrupts the binaries of homosexuality and heterosexuality as well as queer and straight time.

Porter does not see himself as different because he can lay claim to attributes that "he shares with society at large, or at least with that segment of society in which [he] [finds] [himself] and which is, or has been, dominant. He thinks of himself as white, as male, as educated, and as upper middle class" (20-21). The fact that he is a conjoined twin does not necessarily exclude him from society because in his eyes, he is part of the greater 'norm'; his attributes, including his heterosexuality, make him part of the majority and give him cultural capital. In his eyes, these factors outweigh his physical difference and partially save him from being 'othered'; "straight men are part of the 'normal' world; [...] they are the way they're *supposed* to be [...]" (21; his emphasis). As Porter's story unfolds, it is suggested that his life will follow a normative path. He has a serious girlfriend in high school; he goes to college and meets the girl that he eventually marries; and he fathers fraternal twins: a girl and a boy.

Yet, Porter's path is constantly threatened by Owen's. Owen explains, "coming to terms with [his] own homosexuality had been relatively easy; it was

possessed of its own inevitability" (107). What he describes is supported by Gordon's observation that

sexual orientation is *not* applied to the subject as soon as he or she has been assigned a sex and a gender. Although it will invariably be understood in retrospect to have been immanent in the subject all along, it is constituted in the first place as an attribute that will not become fully manifest until after an interval corresponding to the cultural categories of infancy, childhood, and adolescence. Sexual orientation, as a predicate, is susceptible to a constitutive "delay". (5; his emphasis)

That constitutive delay for Owen is marked by a series of 'coming out' vignettes that puncture or cut through Porter's life, as well as through the straightforward narrative of the novel. He begins with his brother and continues with his parents, describing the anxiety that accompanies each clear-cut moment of disclosure. His mother immediately attributes his sexual orientation to youthful confusion, especially since Porter, his genetic copy, is about to be married. She ascribes, according to Stockton, to "our culture's [assumption of] every child's straightness" (2009: 7). Owen even suspects that his mother "reinterpreted [his] life history to 'explain' why [he] was gay" (161). Thus, she adheres to "[t]he generic logic of adolescence [that] entails an imperative to inscribe same-sex desires, acts, and identifications as detours or 'snares' in an overarching heterosexual narrative rather than as indices of an imminent homosexual orientation" (Gordon 1999: 7). To their mother, Owen is a danger to the carefully constructed narrative that she has imagined for her sons. She therefore rationalizes Owen's sexual identity as a fleeting crisis in an otherwise flawless trajectory toward heteronormativity. She had always worried that their conjoinment would pose a threat to them having otherwise 'normal' lives, but Porter's engagement reinforced their 'normalcy'. At the same time, however, Porter's engagement also reinforced her perception of Owen as 'behind time', caught in a moment of adolescent sexual confusion and unable to 'catch up' with his twin brother. For a while, Owen's mother becomes more determined to marry him off, even "creating a fantasy universe in which Faith and [Owen's] future wife could play house" (151). His coming out ruined this ideal for her; as an act, it "[functioned] [...] as a (failed) performing of social categories" (Wang 2007: 235).

While Owen retards Porter's development along his heteronormative trajectory, Porter also interrupts Owen's own homonormative time line. In

“Hiding in the Closet? Bisexuals, Coming Out and the Disclosure Imperative” (2007), Kirsten McLean examines how “[s]exual identity development models view coming out as a milestone event which often occurs as one of the last stages that needs to be overcome before one settles, happily, on a homosexual [...] identity” (151). That ‘coming out’ is referred to as a final stage indicates the linearity and future-oriented structure of this homonormative process of sexual identity formation. Ironically, however, the moment in which Owen is meant to reach this milestone coincides with the perceived destruction of Porter’s futurity. When he comes out to his mother, and has positioned himself to officially ‘begin’ his life, she calls him a danger, a “threat to [Porter’s] very future” (156). Later, when Porter is married and trying to start a family, he too attempts to discourage Owen from acting on his sexual desires, reasoning that his own sex life with his wife is “not just for fun [...]. [They’re] trying to have a baby” (184). Beierle points, in this case, to the “logic of reproductive futurism” that Edelman discusses—the desire to protect a future secured by the Child (2004: 17). Owen therefore presents a hazard to the future of their unborn child, according to Porter, but he himself is also invested in this dynamic. As is evident in the novel, Porter may be the one attempting to use the weight of the Child as a means of securing his connection to the future, but Owen cannot disconnect himself from the same pressure—from the “voice [he] didn’t want to hear but that carried the authority of the ages, the weight of tradition and orthodoxy: who was [he], really, to deny Porter his wife and children” (266).

Futurity weighs heavily on both Porter and Owen. For Porter, having children represents a significant marker in the ‘natural’ progression of a lifetime. For Owen, who is still struggling to discover how he fits into the limitations of heteronormative time, the idea of children is life-affirming, even as a concept. He cannot be the point of digression in Porter’s life. He feels the weight of the past and the pressure of the future upon him when Porter and Faith are trying actively to have children, but it is a weight that he feels even after the twins are born. This is revealed in the symbolic gesture of his parents’ removal of “pictures of Porter and [Owen] as infants and toddlers, which [he] had long thought of as talismans of [his] parents’ pride and courage” (273). In their place were “snapshots of the new twins. It was clear Justin and Christina were now the center of [their] universe and

would be for some time" (ibid). Porter represents futurity and the continuation of the family line; even though Owen is opening up his own future as a gay man, Porter's claim to reproductive futurity makes Owen appear stagnant—an embodiment of the very end of time.

In this novel, conjoinment facilitates the disruption of heteronormative and homonormative time lines because, as conjoined twins, Porter and Owen must materially exist in the same time. Owen is "an individual, a discrete entity, and a very private person, trapped in a body that also happens to contain someone else—someone with a decidedly different point of view" (20). Consequently, Owen and Porter are temporally entangled: two separate people existing in the same time, but along different temporal paths. Beierle's text therefore goes further than what Boellstorff sees as the weakness of contemporary engagement with queer time: the tendency merely to situate queer alternatives "within straight time's linear framework" (2007: 230). As conjoined twins, Owen and Porter are—at least in part—a very real example of the "temporality that does not render impossible the potential of a coeval relationship" between queer and straight time (ibid: 243). They point to the possibility of transforming conceptions of both configurations of time.

When Owen's sexual orientation becomes an 'accepted' fact (at least for him), his life begins to move along its own characteristically straight path towards the moment of coming out, but his path must exist collectively with Porter's, both in terms of physical time and the expression of their sexual desires. Sex did not present a problem for the twins when they were young, since there was no outward object toward which they directed their desire. Once both men define their sexual orientation, the sexual act—which in Aristophanes' speech is viewed as a moment of re-unification—begins to 'cut' them apart. There are two effects of Owen's gradual coming out: first, he is no longer as willing to accept that he is a metaphorical cut in Porter's life; he understands his worth as a separate subject, and second, the actual narrative structure of the novel must move beyond a framework that understands Owen as a momentary divergence from Porter's straight path. The novel must adjust to contain both stories equally.

At the same time the novel reveals how Owen and Porter's different time

lines disrupt each others' life courses, it also shows that Owen is not simply 'behind' Porter in terms of established heteronormative markers of growing up or 'outside' of this normative time line of development. Indeed, Owen does eventually have many of the same experiences as his twin. At first, as a self-proclaimed "reluctant romantic" (63), Owen is content to "[wallow] in the concept of unrequited love, pining away for a succession of handsome, athletic boys and young men in high school and during [his] first three years at [college]" (63), but he ultimately commits himself to meeting eligible gay men. His first sexual encounter turns into a 6-month 'phase' that he is reluctant to call a relationship, but it does "[make] real [his] homosexuality, which until that time had been entirely theoretical" (114). At this point, Owen's sexuality is something that he has admitted only to himself and Porter. Moreover, he partakes in the same rhetoric his mother uses to devalue his sexuality, thinking of his erotic relation to another man as a 'phase' rather than a 'relationship'. The continued invisibility of Owen's homosexuality means that it still functions as the contaminating and subordinate element of Porter's narrative. Since the boys share a penis, however, and must learn to inhabit and claim agency within the same body, they can no longer participate in what Boellstorff sees as the "apocalyptic aversion to complicity and contamination" of different time lines (232). Their physical entanglement implies that they must also continue to learn to cope with and address their temporal entanglement and somehow embrace that they are simultaneously positioned on two different time lines.

To demonstrate this evolution toward temporal entanglement, which signifies the breakdown between theorizations of time as queer and straight, it is crucial to consider the brothers' sexual experiences, how they diverge, and how they eventually overlap. Their first sexual experience with another person occurs when a female fan of their band performs oral sex on them. Porter submits to the experience without hesitation, able to direct his desire toward the girl, but Owen tries "in vain to resist the feeling, clenching [his] teeth, not wanting to surrender, [...] wishing, if anything, that he was shooting [his] stuff down Bandana Man's throat—and that is what allowed [him] to relax, to unclench" (55-6). In the months that follow, as Porter indulges in a number of sexual trysts, including penetrative vaginal sex, Owen manages to distance himself, and with practice is

even able to “insulate [himself] from the matter at hand” (61). Despite Porter’s sexual conquests, Owen still considers himself a virgin at this point. He may share a penis, “the very nexus of their commonality”, with Porter, but he does not attach himself to sexual activity that Porter has participated in with their penis (18). Owen, then, positions himself on a different time line than Porter: Porter has lost his virginity and, by having sex with women, has affirmed his heterosexuality. Owen, on the other hand refuses to partake in Porter’s sexual experiences, daydreaming himself ‘out of the moment’ whenever Porter is having sex and looking forward to the time in which he will experience the fulfilment of his own sexuality.

Once Porter meets Faith, his future wife, he adopts a similar protective stance, almost guarding the penis they share. In fact, he will not even allow Owen to masturbate because he does not want to ‘defile’ Faith by introducing thoughts of men into the sexual act. When Owen finally has his first sexual experience (Faith is still unaware that Owen is gay at this point), Porter sets rules of engagement: he does not want Owen to perform oral sex because he wants to “[keep] the business at hand as far away from his face as possible” and he refuses to engage in anal sex (115). Further, Porter (like Owen) disengages completely during sex, “ultimately acknowledging [their] orgasm with as much enthusiasm as might accompany a similar, less glamorous bodily function—a necessary evil, satisfying only in its completion” (ibid). At this point, their shared penis is the location of pleasure and anxiety for both men, yet it simultaneously symbolizes the potential breakdown of the boundaries the two men construct.

Porter’s marriage to Faith begins to collapse the barrier that Owen had established as a means of emotional survival during sex with his brother’s female partners. He admits to becoming, “despite [his] complete lack of interest in the female anatomy, and [his] deep personal embarrassment at having to be present during Porter and Faith’s most intimate moments, [...] an attentive if somewhat reluctant participant in their lovemaking” (176). While he does not openly admit to experiencing pleasure, he does change in his approach to their sexual acts:

Initially, [he] denied even to [him]self that [he] was enjoying the sensations down there. [...] [He] had tried so hard to become invisible that [he] had become intrusive. Initially, this sort of denial extended to discomfort, as well. [...] Sometimes Faith’s hand strayed to [his] arm or [his] side of [their]

chest, and while [he] never said anything, she soon realized that Porter wasn't responding to her touch, that her hand had meandered into [Owen's] territory, and she pulled back, the first few times with a startled apology, eventually with a simple smile. [...] [Owen] wanted her to be able to wrap her arms around [their] back but to think of it as only Porter's back. [He] didn't get any emotional gratification from this, but [he] would be lying if [he] said [he] was unable to take away some sensual benefits from the physical relationship. (176-7)

As soon as Owen is able to open up to Faith about his sexuality, he begins to embrace more fully his options and demand a greater stake in their shared body. While he is respectful of Faith's 'right' to Porter's time, he is less inclined to "sacrifice [his life] for the greater good of Porter and his family" (248) just because he "[is] single, 'alone'—at least from Faith's perspective—and [Porter] [is] part of a family" (ibid). While Owen still submits to the family imperative on occasion, he forces Porter to share the burden of their physicality and recognize his worth as an individual. He forces, in this case, a co-presence and therefore a compromise between himself and Porter. Ironically, then, the seemingly 'final' act of Owen's coming out is made possible through his learning to be 'in the moment' with Porter during his marital intercourse with Faith.

For Porter, the compromise Owen seeks leads to a gradual disintegration of the boundaries between himself and his brother during the latter's sexual intercourse with men as well; the "boundaries between what he [Porter] would accommodate and what he would not blurred, became less distinct" (243). It is in fact this blurriness that threatens to end Porter's marriage. Faith had reluctantly accepted the reality of sharing her husband's penis with a man, but when she accidentally sees the simultaneous pleasure that a man can give both Owen and Porter, rather than merely understand it as a concept, she cannot cope with the situation: "the realization that her husband was a participant in such a thing, [...] with no control over the situation, but *there*, present in the moment" was too much to accept (302; his emphasis). What threatens to cause the breakdown of Porter's marriage is not that his brother has sex with a man; it is the coincidence and entanglement of Owen and Porter's time lines, symbolized through their shared anatomy and the fact that they are co-present in the moment of orgasm.

Toward the end of the novel, Owen and Porter come to accept their physical and temporal entanglements in linear, teleological and future-oriented

time. Yet because of their physical conjoinment and different sexualities, they experience normative time together *as well as* on their own. This coincidence of two time lines offers a powerful alternative to the binary of queer and straight time and helps to challenge the idea that “[w]ithin straight time, it is impossible to imagine two entities in the same temporality [...] without assuming the always already abjected state of the queer subject” (Boellstorff 2007: 243). This temporal entanglement directly opposes a notion of time that is distinctly queer or straight and shows that Beierle’s novel can help to go beyond a reductive criticism or rejection of straight time. Owen’s coming-out story, while initially functioning as a means to ‘cut open’ Porter’s narrative—to reveal the permeability of normative time—becomes equally substantive and more about conflating heteronormative and homonormative time, thus showing how the distinction between queer and straight time collapses. At the same time that Owen, as a homosexual subject, ‘queers’ Porter’s straight time by coming out, he moves closer to establishing his own rather normative time line, thereby exposing the difficulty in thinking of normative time as a strictly heterosexual phenomenon. Ultimately, then, Beierle is able to make problematic the notion that straight and queer time are absolutely opposed. Owen and Porter’s ability to operate as distinct individuals along the same temporal plane opens up the potential for truly alternate readings of time.

Conjoinment & Transgender Identity: *Half Life*

Like *First Person Plural*, Jackson’s *Half Life* treats the complexities of conjoinment by exploring the possibilities of queer time. However, Jackson goes further than Beierle in using queer time to work against notions of the subject as autonomous and self-contained. As the previous discussion has shown, Beierle’s novel unsettles the equation of queer time with homosexuality and straight time with heterosexuality, as Porter and Owen come to share the experience of normative time irrespective of their sexual orientation. Through this experience of temporal coincidence, reflected by Owen and Porter’s shared body, the novel powerfully disrupts the idea of straight time. However, *First Person Plural* remains committed to the teleological trajectory of the coming out narrative, leading towards the establishment of a concrete subject position. Beierle subverts the distinction

between heteronormative and homonormative time, but remains committed to the notion of distinct subject positions linked to discrete sexual identities: Owen and Porter learn to negotiate their shared time lines so as to establish two distinct sexual identities at the end of the novel.

In contrast to Beierle, Jackson's novel about conjoined twins Nora and Blanche Olney is not concerned with sexual orientation. Although Nora is lesbian and Blanche is straight, the difference in their sexual identities is never developed fully in the novel. The reason for this is twofold: for a start, the novel has the reader believe initially that Blanche has been unconscious and inactive for the past fifteen years of Nora's life, leaving it up to Nora to narrate her story. In this sense, Blanche does not actively 'live out' her sexuality. More importantly, however, Jackson's novel is set in a future where sexual orientation no longer seems to matter. In this post-sexual world, debates around sexual identity have been replaced by the focus on conjoinment itself: living in San Francisco, "where Twofers [have] their own paper, the *Two Times*; their own radio show, *Twinspeak*; support groups; political candidates; dance clubs (2, Dos y Dos, the Twostep); and Pride", Nora and Blanche are part of a thriving, politically and socially active minority subculture of conjoined dicephalus twins who were seemingly born as a result of repeated bombings and radioactive fallout in the Nevada desert (42). Through repeated references to Pride, which has come to be associated historically with the process of 'coming out' and establishing a 'true' identity, Jackson links the process of sexual identity formation with the question of conjoinment. As has been shown in the discussion of *First Person Plural*, the 'coming out' narrative is similar to the narrative of conjoinment that strives toward the physical cut—the 'moment when' a doubled-body is severed into two, and two separate identities are established. Jackson complicates this narrative and its underlying linear and teleological trajectory through various means. For a start, the futuristic world in which Nora and Blanche live has learned to embrace conjoinment, so that 'coming out' and Pride no longer celebrate the emergence of a 'clear-cut' identity. Rather, the post-sexual culture of Jackson's novel inverts this process so as to glorify the unsettling of straightforward identity boundaries.

Importantly, however, Nora does not partake in this celebration of conjoinment. Quite the contrary, the first page of the novel is a copy of a 'release

and waiver' that Nora has signed to have Blanche surgically removed. Given the affirmative cultural climate, Nora's desire to be separated from Blanche and to establish her own independent identity is not easily explicable or self-evident. *Half Life* takes seriously Nora's struggle with conjoinment and comments critically on an all-too-easy affirmation of 'twoferness', in turn caricaturing queer celebrations of fluidity today. The conjoined body in *Half Life* is presented as similar to the idealized transgender body today, which has, according to Halberstam "emerged as [...] a kind of heroic fulfilment of postmodern promises of gender flexibility" (2005: 18). Like Halberstam in her work on queer time and the transgender body, Jackson's novel does not use conjoinment to uncritically celebrate a fluid understanding of the subject, but to carefully explore the demands the unusual body places on narratives of the self. Instead of sexual identity formation, which is explored in Beierle's novel, Jackson focuses on the normative time lines of gender identity formation, which are challenged by reading conjoinment in tandem with transgenderism. Despite the focus on gender identity, Jackson is less interested in specifically gendered dynamics of individual development. Rather, she uses the challenge that transgender narratives pose to conventional accounts of individual development to explore the relation between the body, subjectivity and temporality more generally.

The connection between the conjoined and the transgender body is subtly established in the first half of the novel, which traces Nora's longing for surgery in a bid to make her body 'match' her sense of self. The similarities between separation and sex-change surgeries are described in more explicit terms in the second half of the novel. Nora has found a renegade surgeon in London who is willing to perform her surgery. As she is walking through the clinic, she passes post-operative singletons, "some of them heavily bandaged. Those who were not seemed to thrust the still red and sore remainders up and out like bold new genitalia" (278). Thus, the separated body is directly linked to the new anatomy of postoperative transgender subjects. Nora further details how the post-ops seemed to "disassociate themselves from the anatomies they had left behind" and participated in a secret ritual to commemorate a new beginning, in which they were reborn into a single body (291). Here, Jackson links transgenderism and conjoinment by pointing to the shared temporal predicament of having to forget

or rewrite an undesired past in order to celebrate a moment of rebirth and construct a clear-cut identity. These temporal tropes are central to conventional narratives of transsexuality in which the transgender subject seeks “to pass [through the transition process] and assimilate as nontranssexual” (Prosser 1998: 11). Sandy Stone points to the temporal implications of transitioning when she describes passing as “the effacement of the prior gender role, or the construction of a plausible history” (2006: 231). Similarly, Halberstam argues that cultural representations of transgender characters often construct his or her dilemma as that of having “to create an alternate future while rewriting history” (2005: 77). Such stereotypical accounts of transgender lives are similar to coming-out stories in that they rely on normative figurations of time as linear, teleological and future-oriented, leading from the birth in the ‘wrong body’ to the turning point of transition after which the transgender subject passes in his or her newly established gender identity.

Nora’s narrative initially follows a similar trajectory: the surgical separation from Blanche appears to be the only means through which she can maintain the singular identity that she has established in Blanche’s sleepy absence. For Nora, separation surgery is her only chance at a ‘normal’ life initiated by the ‘cut’—her rebirth into the life she feels she was supposed to have. As in other cultural representations of separation surgery discussed in previous chapters, the prospect of surgical separation offers Nora hope and operates as the rationale and destination for her decision to remove Blanche from her body and life. According to Jay Prosser, the common depiction of the transsexual subject as someone ‘stuck’ in the wrong body points to “the refusal of body ego to own referential body” (1998: 77). The need for sex-change surgery derives from the same feeling: “If the body is not owned, it is in this experience of the body—not *my* body—that surgery intervenes” (78; his emphasis). Similarly, Nora’s understanding of herself as a single subject does not match the body she finds herself in—a body that she does not own—and she seeks to correct this ‘mistake’ at all cost. Nora’s feeling of alienation in her own skin is made worse through her dawning suspicion that Blanche is slowly beginning to become conscious again. When unexplainable incidents occur with increasing frequency—Nora compiles a

list of items that are thrown without her intention, for instance—she decides to “commit a murder” and rid herself of Blanche (130).

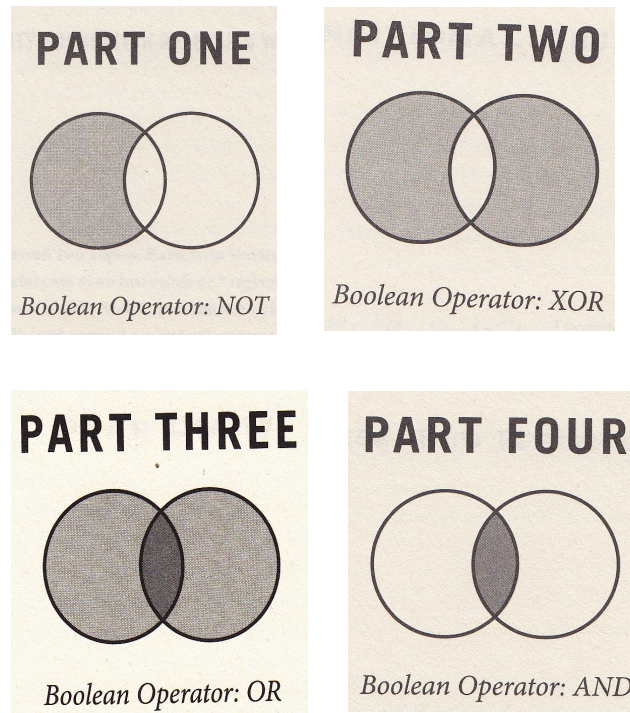
Like the transgender subject seeking to efface the previous gender role in a bid to pass, Nora’s understanding of herself as a singleton trapped in the wrong body is also crucially dependent on forgetting her shared past with Blanche. Nora describes that her life began officially when Blanche went to sleep 15 years ago. This, according to Nora, is when “[their] body was [hers]. It grew up. [She] grew up, and Blanche was like a vacation puppy too dumb to bark at the shrinking license plate and the desperate faces tinged with aquamarine behind the glass” (9). In this image, Blanche is presented as an unwanted family member who is simply left behind while Nora’s own journey of development as a single subject begins. Importantly, as in conventional transgender narratives, this new understanding of the self is dependent on an erasure of the past: Nora “[does not] remember much of what came before [Blanche fell asleep], and what [she does] remember lacks heft” (ibid.). Blanche comes to be associated with a past Nora wishes to rid herself of just as in conventional transsexual narratives the gender assigned at birth comes to be linked to a past that needs to be erased or rewritten.

Despite this initial denial of her shared past with Blanche, Nora increasingly engages with their shared life before her sister fell unconscious. Initially, she motivates these flashbacks by saying that she must go “back to the beginning” if she is ever to be able to cut herself, physically and psychically, from Blanche (ibid.). She explains that “[in] disentangling two pieces of string, one looks for the ends” (ibid.), which points to her desire for a linear narrative with a clear beginning and end. Nora self-reflexively acknowledges her active role in (re)creating the past as narrator. Narrating the moment of her and Blanche’s conception, for instance, the sisters exist on two levels simultaneously: their physical conception occurs on the level of the story—NOW—“right now—yes—wait—yes, right now” (14)—as well as the level of discourse—NOW, where they are conceived by Nora and her “half-teaspoon of ink” (16), an image reminiscent of the ‘standard’ volume of ejaculate per emission. Here, Nora becomes both writer and creator of her and Blanche’s lives. Their story begins not only with their parents’ sexual encounter, but also with her recreation of the past.

As the novel progresses, however, Nora learns that the past is not hers alone to rewrite or to 'cut out'. Indeed, it is through her narrative engagement with the past that the straight time line leading towards separation surgery and the establishment of a clear-cut identity is increasingly unsettled. *Half Life* charts this development in four sections, which are organized by Boolean operators: NOT ("I, not you."), XOR ("Either of us, but not both."), OR ("Either or both of us."), and AND ("The intersection set.") (386). The descriptions of these operators, which are said to "govern our relations with the other—the other in the world, and the other in ourselves" are given in the Siamese Twin Manual Nora consults frequently and which is reproduced towards the end of the novel (385).³⁶ Corresponding to each operator is a Venn diagram that illustrates visually the evolution of Nora's relationship with Blanche, "from static NOT to dynamic AND" (ibid). As Nora begins to understand more fully and accept Blanche as integral to her life, the Boolean operator (and the corresponding Venn diagram) evolves to the more inclusive. In part one, NOT, Nora does not acknowledge Blanche beyond the fact that they are physically connected. Blanche is an intrusion—a mass of flesh that does not possess value. The Venn diagram is consistent with this lack of relationship; there is no Blanche, only Nora, so only one circle of the diagram is shaded. Even the overlapping part remains unfilled. In part two, XOR, Nora acknowledges Blanche's existence but only as that which directly opposes her own. In this case, either Nora or Blanche can exist, but not both; one is expendable. Likewise, the related Venn diagram shows two circles, both shaded, but with an un-shaded overlapping segment; there is no common ground. Part three, OR, corresponds to Nora's gradual acceptance of Blanche as a fundamental part of her own self, but also as an individual with her own selfhood. The emphasis in this section is on how each girl represents part of one whole. The Venn diagram depicts two shaded circles, and the overlapping segment is also shaded. Finally, in part four, AND, Nora reaches an understanding of herself as intimately connected to Blanche, inseparable both physically and psychically. It is in this final section that it becomes impossible to discern fully where one twin ends and the other begins and in which Jackson reveals her criticism of all binaries—Nora/Blanche,

³⁶ Boolean operators are commonly used in programming and database/internet searching. They are the means through which logical relationships among search terms are constructed. These operators are often illustrated with Venn diagrams.

self/other, and even awake/asleep. The Venn diagram in this final section advances further to express the emphasis on the overlapping segment (now colored), rather than the individual circles, which are left un-shaded.



The relation between subjectivity and temporality represented in the VENN diagrams is made explicit when Nora's roommate, Audrey, conceptualizes Nora's relationship with Blanche in terms of time:

"Actually, I *believe* what you told me is that Blanche is in charge of the past and you're in charge of the future, but that's NOT talking. The past is part of the future, you know, which is why you have more in common with Blanche than you want to think, and it might behoove you to get to know her. That's not charity, that's self-preservation. Cutting off your past is like cutting off, I don't know, your own *head*. What's left, for Venn's sake? The future? What's that? The future doesn't exist!" (334).

Here, the temporal implications of the final diagram become apparent: the colored overlapping segment in the middle signifies not only the intersection of Blanche and Nora's body and subjectivity, but also the relation between past and future, which cannot be neatly separated. This reveals the insufficiency of the linear, teleological and future-oriented time lines that drive both the desire for sex-

change surgery and passing as well as the desire for separation surgery and life as a singleton. Since *Half Life* continuously points to the similarities between conjoinment and transgender, the novel's critique of the straight time of transition—into a new gender or non-conjoined self—needs to be read in conjunction with work by scholars like Prosser and Halberstam, who have shown that new understandings of transgender narratives and temporalities are emerging, which equally challenge the normative temporal trajectory of transitioning and passing.³⁷ Thus, Prosser argues that “refusing to pass *through* transsexuality [in order to pass *as* a nontranssexual man or woman] [...] [and] no longer typically ending transition, transsexuals are overtly rewriting the narrative of transsexuality—and transsexual narratives—as open-ended” (1998: 11; his emphasis). Halberstam also participates in this search for different ways of thinking about transgender lives, exploring “the [queer] potential to open up new life narratives and alternative relations to time” (2005: 2).

In *Half Life*, Jackson explores queer time through the representation of surgery, central to understandings of conjoinment and transsexuality. With regard to conventional transsexual narratives, “sex reassignment surgery is considered the hinge upon which the transsexual’s ‘transsex’ turns: the magical moment of ‘sex change’” (Prosser: 63). The surgical ‘cut’ in sex-change surgeries is similar to separation surgeries in that it serves to support a normative understanding of time: it represents the telos of the journey towards normalcy, which is associated with the single or passing subject. Jackson, however, disturbs this relation between surgical intervention and ‘normalcy’ by exploring the queer temporality of surgery. Instead of facilitating a straightforward transition into ‘normalcy’, it is through the experience of surgery and the surgically altered body that Nora is made aware of the temporal entanglements that connect her to Blanche in ways that cannot be ‘cut’.

In the days leading up to the surgery in London, Nora feels haunted by the past and uses a strikingly physical metaphor to describe the demands the past

³⁷ Prosser’s work on transsexual narratives was produced before the ‘turn’ to queer time in queer studies and therefore does not draw on the same terminology as the other theorists discussed in this chapter. However, Prosser’s engagement with the narratives and temporalities of transsexual autobiography does anticipate and feed into later theorizations of related questions articulated under the banner of queer time, such as Halberstam’s work in *In a Queer Time and Space*.

places on the present: “The details of the past float up and adhere to one another, forming little tumors of plausibility and consequence. This happens as if by some automated process; stories take shape, they thicken and grow together” (244). Blanche represents this cancerous past, which Nora wishes to excise through surgery. That this neat removal of the past might not be possible, however, is indicated earlier in the novel when Nora recalls her grandmother, who lost her breast to cancer in the fifties. It is the memory of her grandmother’s absent breast that allows Nora to understand the power of “a missing thing [which can] make a mighty showing of its absence” (157). Importantly, Nora compares herself *and* Blanche to the cancerous breast, saying that they both “were children of National Sadness” (ibid). Both their grandmother’s cancer and their twoferness were caused by the atomic fallout, and just as she had seen people stare at the voided space where the breast had been, Nora saw that she and Blanche were equally scrutinized. But the comparison to the missing breast also links Nora and Blanche’s body quite literally to the question of whether the past can ever be left behind, a question raised specifically by sex-change surgery, which is once again alluded to since mastectomies are used not just in cases of breast cancer, but also in female-to-male sex-reassignment surgeries. The absent yet present breast points to the fact that a removal or any other kind of surgical cut *produces* through wounds and scars a memory of that which is supposed to be left behind. In this sense, the comparison to breast surgery that leaves an unwanted and haunting absence indicates the potential trauma of separation surgery.

Ironically, it is in the operation room—the place where Nora literally wishes to cut out Blanche and the past she represents—that she is forcefully reminded of her sister’s presence in her life: just as Nora is about to be administered anaesthetic for the surgery, she has a moment of hesitation and wonders “[h]ow she has become this person? [...] Half [her] stock of memories were about to be subtracted from [her]” (314). She begins to dream about her new body, devoid of Blanche, but visualizing herself on the operating table, she suspects that something is wrong. Helpless, she realizes, just as a radical pro-conjoinment group, the Togetherists, storms the clinic, that it was *her* head that was about to be removed. In one of the novel’s major twists, it is revealed that her ‘sleeping’ twin somehow managed to complete the necessary paperwork for

surgery as well, and the surgeon decided that Nora was the extraneous head, the “malignant tumor” that was expendable (322).

The idea that Blanche’s passivity might have been part of Nora’s imagination or that Blanche was active while Nora was asleep radically challenges the concept of Nora as the autonomous subject who is simply trying to make her body match her self-understanding. Here, Nora has become the ‘tumor’ that needs to be removed, allowing Blanche to claim her own life and her own single body. Blanche—the supposedly passive appendix to Nora’s body that all of a sudden asserts its own agency—is reminiscent of Freud’s notion of the uncanny, which he associates with body parts that move without one’s knowledge. In his essay on “The Uncanny” (1919), Freud explains that the uncanny emerges once “the distinction between imagination and reality is effaced, as when something that we have hitherto regarded as imaginary appears before us in reality” (2001.17: 244). Blanche’s surprising agency is uncanny in that it troubles the distinction between the imagination and reality: Nora’s reality in which Blanche is unconscious and passive might have been a dream all along; Blanche’s unconsciousness might be Nora’s consciousness and vice versa.

The uncanny also has an important temporal dimension in that it represents a repressed past that hauntingly disrupts the present. Whereas Blanche has come to be associated with the past throughout the novel, her uncanny presence troubles the distinction between present and past. Given the associative chain that connects Blanche, the past and the tumor, it is clear that Nora—whose head is about to be removed—now also comes to stand in for the past. There are two different time lines that collide and that are no longer structured or anchored by Nora’s narratorial presence in the story. This radically challenges the normative time line of passing/conjoinment surgery: it has been argued that passing like separation surgery consists of leaving behind the past identity (of the opposite gender or the state of conjoinment). Due to Blanche’s unexpected assertion of her own agency, which powerfully troubles the distinction between past and present, absence and presence, it is no longer clear how to move on from the past since it has been effectively doubled: Nora *and* Blanche inhabit the past *and* present. As a result, the straight time line that leads towards surgery and into ‘normalcy’ is queered.

Nora responds to the thwarted surgery by accepting Blanche's presence in her life, a process intimately related to her reimagining and rewriting of the past. Prosser points out that memory is central to the experience of the body; in contrast to people undergoing reconstructive surgery, transsexuals are not literally trying to assemble a body they once had. Rather, "sex reassignment surgery is a recovery of what was not" (1998: 84). This desire to construct an imaginary past fed into Nora's initial decision to undergo surgery and become a singleton: she was trying to 'recover' a past that has never been, a past in which she has always been independent of Blanche. After the failed surgery, however, Nora begins to remember a *shared* past and recognizes that she herself was responsible for tricking Blanche into silence 15 years earlier. The reason behind her desire for Blanche to disappear was that Nora felt responsible for her grandmother's death and did not want her sister to give them away. Exerting the control over her twin that she had been testing since they were young children, Nora convinced Blanche that she was solely to blame, and since there was no other way to ensure her silence (Blanche was weak, she told herself), she must "put [Blanche] somewhere [she] couldn't hurt anyone else. Somewhere quiet" (413). With that, Nora was alone, reborn, "a self-made self", who felt suddenly complete without her twin (415). It is the thwarted surgery that allows Nora to recover this different past—one that she had previously hoped to forget. As soon as Blanche reasserts her presence in Nora's life, refusing to be written out of the story or left behind, Nora is forced to rewrite the past. Recognizing that she had constructed her independence all along, Nora's understanding of herself and her relation to Blanche changes.

After the failed surgery, Nora and Blanche return to America. In a series of diary entries, the two girls' perspectives merge, illustrating Nora's increasingly dialogic relationship with Blanche. Nora admits that she can no longer tell with any certainty who is authoring any given part of the narrative. She knows simply that she is no more or less awake than Blanche; her 'awake' is Blanche's 'asleep', and perhaps Blanche's 'awake' is Nora's 'asleep'. This is all but confirmed when Nora finds entries in her diary that she does not remember writing, and she begins to believe that "Blanche's dream world is merging with [her] waking one" (345). This conflation of past and present is reminiscent of Freud's mystic writing-

pad, described in his essay “A Note Upon the Mystic Writing Pad” (1925), which “provides not only a receptive surface that can be used over and over again, like a slate, but also permanent traces of what has been written” (2001.19: 230). The past can never be fully erased and distinguished from the present. It has the potential to haunt the present and alienate it from itself. This resistant past powerfully disrupts the straight time lines of sex change and separation narratives. It also makes problematic the concept of a normative passing or single subject imagined as the ultimate goal of these narratives.

Towards the end of the novel, Nora comes to realize that she has to acknowledge this disruption of her present and her own subjectivity: she cannot excise Blanche without eliminating herself. She learns to accept that “the present-tense self has no identity of its own, it’s just a bitty band of flesh between memory and anticipation” (364). The comparison of the intersection between memory and anticipation to a ‘band of flesh’ refers to the physical material that literally connects Nora and Blanche. Nora had previously sought to rewrite the past and ‘cut’ her connection with Blanche in a bid to claim her future as a singleton. Now, she learns to accept that it is only through her physical connection with Blanche that she can negotiate her own understanding of self, past and future. This is reinforced when Audrey explains to Nora, “‘We’re blurry, thank Venn. Our grey area [...] is our window’” (368). This reference to ‘grey’ is particularly relevant to Nora and Blanche, whose middle names are ‘Gray’ and ‘Grey’, respectively.

Shelley uses conjoinment, together with the implied referent of transsexuality, to highlight the complex relation between temporality and subjectivity and to point to the inadequacy of the straight time lines promising to establish an autonomous and independent self. Instead of radical fluidity and indeterminacy, however, Shelley’s novel does not deny the constitutive significance of difference. At the end of the novel, Nora acknowledges that her self is recognizable and definable only by what it is not, namely Blanche, who is simultaneously a part of Nora and a distinct individual in her own right. Nora writes:

A cleft passes through the center of things, things that do not exist except in this twinship. The cleft is what we sometimes call *I*. It has no more substance than the slash between either and or.

I have spent my whole life trying to make one story out of two: my word against Blanche's. But we are only as antithetical as this ink and this page. Do these letters have meaning, or the space around them? Neither. It's their difference we read. [...] This is her story, which is ours. (433)

The 'cleft' symbolizes both the present and the self, which are only tangible because they can be differentiated from what is on either side of them. The forceful physical imagery of the 'cleft' and the 'slash' once again refer to the surgical 'cut' that seeks to efface the past and establish an autonomous self. However, in Nora's metaphor, the 'I' is constituted only by what surrounds and exists in relation to it: the present has meaning because of the past and future, while the 'I' has meaning because of its relationship to the other. Nora has been thinking all along that her narrative was hers alone, but the black ink on the page has no meaning without the blank space on which the letters of the words are written. In the same way, Nora's story has no meaning without Blanche's; it is merely a 'half life'. Nora does not renounce the right to her own subject position, but comes to accept that the self is a necessary fiction wrought out of the physical, temporal and textual entanglements that connect her to Blanche.

Instead of a happy ending in which the contradictions between self and other are harmoniously resolved, Nora and Blanche's story remains strikingly open. The last line of the novel—"Nora?" I say"—raises doubts as to who has been narrating the story all along (437). The speaking voice might belong to an awakening Blanche and uncertainty remains over whether Nora will answer. Perhaps she has written herself out of the story or Blanche has now silenced her. It is equally possible that this is still Nora speaking, questioning and seeking her own self. The novel's open-endedness indicates the text's resistance to closure and certainty. Although it is impossible to identify who is speaking, however, Shelley insists on the very significance of the 'I'.

The constant linkage of conjoinment, transsexuality and surgery in *Half Life* serves to highlight precisely this stubborn desire for a clearly defined subject position. Nora does not ultimately undergo surgery and cannot establish a fully autonomous and distinct subject position, but her desire for separation is taken seriously. This is brought out even more strongly since she lives in a culture that celebrates conjoinment and has supposedly moved on from the need for a 'clear-cut' identity. Similarly, the transsexual subject's insistence on sex-change surgery

is sometimes viewed as backward given what Prosser identifies as the queer displacement of the material sexed body (1998: 52). Shelley does not do away with this desire, but shows that it cannot be accomplished by 'cutting off' the past altogether. Instead, as her use of physical imagery throughout the novel shows, the body itself comes to be understood as a haunting medium that carries remnants and traces of the past, with which Nora needs to engage. Thus, Nora and Blanche's conjoinment is not something that can be 'fixed' through surgery. Instead, it demands a complex process of textual and temporal negotiation that resists the normative straight time line of transition and separation.

Concluding Remarks

This thesis offers a response to the heightened interest in the figure of conjoined twins in contemporary fiction and culture. The previous discussion has positioned representations of conjoinment within the history of the monster, freak and patient, and it has engaged critically with different approaches to the body, models of disability, and figurations of sexuality and time. In doing so, my research has explored the different ways in which conjoined twins are represented in a variety of media, including documentary film, television and literary fiction. It has also analysed how representations of conjoined twins both reinforce and challenge social norms and ideologies, primarily with regard to physical difference and subjectivity, but also sexuality.

Because one of my arguments throughout the thesis has been that representations of conjoinment open up a critical space of discussion and negotiation, it would be counterintuitive to close down the debate provoked by representations of conjoined twins by means of a conclusion. Instead, it is more appropriate to gesture toward further areas of consideration that arise from my research. As I have argued in the introduction, through the process of representation, figures and images of conjoinment come to stand in for actual conjoined twins and other individuals with non-normative bodies more generally. For this reason, representations of conjoinment raise important ethical and political questions. The main focus of my project lay on the discussion and analysis of representation in its various forms and it was not my primary aim to develop, promote or criticise either social or medical strategies of engaging with conjoined twins. Nevertheless, through its engagement with disability studies, my research has shown that representation can pose a powerful challenge to social stereotypes and stigmas, for instance, by exposing how arbitrary social norms influence understandings of physical difference or by challenging views of conjoined twins as passive and voiceless victims. While it is not the primary aim of this thesis to articulate political goals and strategies, any critical discussion of the representation of a marginalised group of people like conjoined twins has the potential to lay the groundwork for various forms of action. Furthermore, as emphasised in my introduction, social and political engagement has become an integral part of the work produced within cultural studies, and cultural studies

scholars, as a result, have the potential to exert some degree of influence in transforming ideologies, changing the ways in which people perceive themselves and each other, and encouraging social change and political action.

Ethical and Political Implications of Representation

In the opening pages of her epilogue to *Hermaphrodites and the Medical Intervention of Sex* (1998), Dreger admits the following about her work on intersex: “The book would look very different if it could have included first-hand accounts telling us how people labeled ‘hermaphrodites’ in the nineteenth century saw and represented their own bodies and lives” (167). Unfortunately, however, “hermaphrodites, like the poor and sick, have left few personal archives” (ibid). The late twentieth century, as Dreger goes on to say, witnessed an upsurge in stories from “medicine’s subjects”, but this is not the case for all medical patients (ibid: 168). Conjoined twins, for example, have often remained silent and the rarity of the condition has resulted in a comparative paucity of first-hand accounts of conjoinment. While the Hensels, Schappells, and others have given some insight into their own experience of conjoinment in documentaries, on television shows, and in print interviews, there are no sustained personal, autobiographical narratives told directly by conjoined twins themselves.³⁸ Representations of conjoinment, therefore, often claim to speak for and on behalf of conjoined twins and can powerfully reinforce ideologies. However, when subjected to critical interrogation, such representations can also open up to debate important ethical and political concerns about conjoinment.

Separation surgery is the most widely debated ethical issue with regard to conjoinment, and it is a point of contention that raises awareness of the ways in which ideologies of normalcy affect real lives. As chapter two of this thesis demonstrates, the bodies of conjoined twins are constructed as incomprehensible, and therefore insufferable, which, in turn, justifies surgical intervention. Medical documentaries focus on separation surgeries, which reaffirm social and cultural

³⁸ In 2009, Erin Herrin released a biography detailing her family’s journey from finding out she was pregnant with conjoined twins, Maliyah and Kendra, to their separation in 2006. Their family also maintains a website and Facebook account where Erin posts regular updates about the twins’ progress, yet the twins themselves remain voiceless, still too young to speak for themselves.

norms by promising to repair or rehabilitate those unusual bodies. In the documentary *Conjoined Twins* (2000), for instance, Dr. Rode explains: "My own philosophy and that of our department is that Siamese twins are born to be separated". His colleague at the University of Cape Town, Professor Jonathan Peter, shares the idea: "I think the ethical decision about separating twins is, is (sic) quite established and I think it is the right thing to do, so the risks are worth taking." Their view of conjoinment as a purely bio-technical problem does not recognize the full scope of the surgical split; they do not acknowledge that "the consequences of what is effectively a phenomenological split, as well as a surgical procedure, might need to be addressed with the same gravity afforded the clinical planning" (Shildrick 2008: 37). In other words, there is no consideration of the residual psychic effects of separation surgery—only affirmation that the body of conjoined twins is so deeply intolerable that separation must be attempted irrespective of the risks to the twins' psychological wellbeing and personal agency. Indeed, separation surgery is often promoted without any consideration (beyond basic issues of physical wellness) of whether medical normalisation is the best choice for the individuals affected. Unlike the singular case of Ladan and Laleh Bijani, 29-year old Iranian craniopagus twins who made the decision to attempt separation but who died shortly after their 53-hour surgery, parents and doctors usually act as agents for conjoined infants and children. They make the decision to separate, but they do so, according to Christine Overall, from the perspective of their own "idealization of singletons' embodied personhood, fail[ing] to notice that embodied personhood is crucially different for conjoined twins—different with respect to physical independence and the relationship to the corporeal, bodily ownership and authority, and self-awareness and privacy" (2009: 69). From their point of view as singletons, conjoinment seems oppressive, and 'rescuing' conjoined twins from their shared body is seen as a humanitarian and ethically sound undertaking.

Furthermore, these particular separation-focused documentaries tend to omit testimonies from conjoined twins themselves. Of course, the documentaries discussed involve young children who cannot perhaps articulate their own feelings yet, but my point is that there is recorded evidence where conjoined twins express their preference for conjoinment and explicitly reject separation surgery.

Despite being subjected to various medical procedures at Moscow's Paediatric Institute for six years, and then being sent to live in a hospital until they were teenagers, Masha and Dasha Krivoshlyapova, for example, have made it clear that they would never consider separation. In *Conjoined Twins*, Masha admitted, "We'd never agree to such an operation. We just don't need it." Her sister agreed: "We're 50 now. We'll stay like this for the rest of our lives" (2000). Reba and Lori Schappell repeat the same sentiment in the documentary. Lori says, "We never wanted to be separated, we never do want to be separated and our families never ever wanted us separated because we fully believe that God made us this way and he had a purpose for us and you do not ruin what God has made" (ibid). Her sister, Reba, shares this belief:

You have to look at how the individual who is set conjoined perceives themselves (sic). If you perceive yourself positive the public will look at you positive. Maybe it will take a while, but even if the public doesn't look at you positive, if you're positive enough you're not going to give a, a hoot and anny (sic) of how they look at you. You're going to like yourself the way you are. Do you, do you under... I hope the public out there does understand this. (ibid)

Reiterating these points, Ronnie Galyon, one of the world's oldest conjoined twins, told Emma Cox, a reporter from British newspaper, *The Sun*: "Our belief is this—let God separate us. Let the good Lord separate us. God made us, let God separate us, not using surgical knives" (2009). Given the choice, it is clear that none of these individuals would choose to experience life any differently than they do, as it is the way that they have learned to understand their lives as embodied individuals. Brittany and Abigail Hensel, who I discussed in chapter three, have even emphasized that conjoinment helps, rather than hinders them. In *Joined For Life: Abby and Brittany Turn 16* (2006), Abby explains: "We never wish we were separated because then we wouldn't get to do all the things that we can do...play softball, meet new people, we wouldn't have been able to do that, and run, and we wouldn't have been able to do sports and stuff like that". Clearly, they view their body as the means through which they can be included in, rather than excluded from, the same 'normal' activities that singletons enjoy. While they obviously experience life differently, they recognise (and even emphasise) the advantages of remaining conjoined. It may be that adult conjoined twins have not considered separation because of the diminished odds of recovering fully (or even surviving)

such an invasive procedure, or because by the time they have reached maturity, most conjoined twins are thriving in their shared body. As a result, their voices interrupt and complicate the ideologies of normalcy underpinning some representations of conjoinment. Such testimony from conjoined twins who are leading productive lives and see themselves as individuals despite their shared bodies can therefore serve to challenge the medical imperative to separate children born conjoined, even when the result could be physical or mental disability (trading one stigmatizing difference for another) or even death to one or both of the twins.

Interestingly, however, the medical documentaries that I have examined in chapter two simply omit these voices. They do not allow for a critique of the ideology of a normative body and do not open up the possibility for viewers to be made aware of the process through which certain ideals and norms are naturalised. Two separate bodies are the goal toward which surgeons are working, and this is presented as the only acceptable outcome for conjoined twins. The aim of chapter two is to draw critical attention to the fact that medical documentaries make non-normative bodies appear intolerable and ‘unliveable’ precisely because these bodies are judged and evaluated from the point of view of those who occupy (albeit temporarily) a ‘normate’ position. The norms and ideals upheld in these documentaries are, as Dreger reveals, in part created by medical professionals, who “whether they mean to or not, help to construct social anatomical norms, as well as people’s personal and social identities” (2004: 144). Moreover, society is increasingly demanding interventions in physical appearance, for instance, through cosmetic surgery, in order to achieve a more ideal appearance. Given these closely aligned factors, one must wonder whether the problem begins with medicine, society, or representation. To answer this question, I defer once again to Stuart Hall’s estimation of representation as a constitutive agent and the fact that the process of representation immediately calls forth questions of meaning and power. It is therefore crucial to expose the process of representation in a bid to “*change* the relationship of the viewer to the image”—to identify and criticize the systems of power that uphold normative ideologies (1997: 21; his emphasis). If this can be accomplished, then stereotypes and other social and cultural norms can be challenged.

In paying critical attention to ideology and representation, it becomes possible to address a key question raised by Alice Dreger in *One of Us* (2004): “Why not change minds instead of bodies? Why not—like the campaigners on behalf of women’s rights and civil rights and gay and lesbian rights—think about the social nature of the problem [...] and start there?” (149). This is a crucial argument, and it is one that disability studies has engaged with since the end of the twentieth century when it began postulating a social model of disability. Rather than see non-normative bodies as errors to be corrected by medical intervention, the social model (as I elaborate upon in chapter three) established a difference between impairment and disability, labelling disability as socially constructed. As Niall Richardson concludes, “This was very important politically, as the social model changed the trajectory of disability activism” (2010: 169). Chapter three illuminates this shift by examining documentaries that uphold a social model of disability; instead of surgically altering the bodies of conjoined twins through separation surgery, these documentaries highlight and seek to challenge social attitudes toward individuals with unusual anatomies. In insisting on the social nature of disability, they adopt the social model commonly endorsed within disability studies.

However, this shift in paradigm from medical to social has been equally problematic, and the documentaries relying on a social model of disability fall as short as medical documentaries in representing the actual lived experience of conjoined twins. The project of changing minds rather than bodies, proposed by disability studies a few decades ago, is helpful in terms of articulating a powerful political agenda, but the challenge it poses is also incomplete. As the discussion of documentaries in chapter three shows, the inherent risk of these representations is that people with non-normative bodies (or other differences for that matter) will come to be seen as victims of society rather than victims of biology. If this is the case, then what has actually been achieved in these representations? While they do potentially make viewers more aware of their own prejudices, they are not radical enough because they leave the body out. In doing so, they simply shift the paradigm; if the body is not the issue, then surely it must be society. What they miss in their representation of the Schappells and the Hensels is an opportunity to present disability as a complex experience of self and society.

There is more to 'any body' (be that body a conjoined twin, a person that deals with another type of difference, or a supposedly 'normal' person) than just a physical or just a social component.

The recent theoretical return to the body has revealed a gap in disability studies, and as I describe in chapter four, disability studies scholars and activists, as well as disabled people have responded. Surely, since impairment is the material foundation of disability, any representation that does not acknowledge that biological difference has the potential to do harm to conjoined twins, and disabled people more generally. It is neither enough to change our minds about disability nor just to assume that all disabled people will experience their impairment in the same way. By doing so, we negate individual experience and collapse all disability into a single category of difference. This assumed collective experience further strengthens the barrier between 'us' and 'them'—between spectacle and spectator, victim and victimizer, abnormal and normal. Chapter four of my thesis responds to this point, highlighting a more innovative, holistic approach to disability. The texts I discuss draw attention to the potential of representations of conjoined twins (and, by extension, disabled people) to produce "new kinds of knowledges, [...] new kinds of subjectivities, [...] and new dimensions of meaning which have not been foreclosed by the systems of power which are in operation" (Hall 2005: 22). As has been pointed out above, the voices of conjoined twins themselves are not heard very often. However, there are indications that this wider discourse on conjoinment is also creating rhetorical spaces in which conjoined twins can and do speak for themselves. This is the case in some of the documentaries discussed throughout the dissertation and is also evident in the fact that the Hensel twins are filming their own reality show, set to debut on the American network *TLC* in August 2012. While the reality show format will inevitably mediate and shape the representation of the twins' personal experiences of conjoinment, it can nevertheless offer a means to combat the silencing of their voices. As a whole, such depictions of conjoinment can make society more alert to the complexities of this particular physical difference and encourage viewers or readers to challenge their own assumptions. As such, these texts at least create a cultural awareness and the potential for critical thought,

which can translate into ethical and political action or at least open up a pathway towards it.

Conjoined Twins as Metaphor

In addition, representations of conjoinment do not only serve to reference the specific lived reality of conjoined twins. As has been argued in the introduction and demonstrated in each chapter, the figure of conjoined twins often acts as a screen onto which wider topical concerns, interests and anxieties are projected. In the present moment, for instance, many representations of conjoinment reflect current debates about the body, subjectivity and sexuality, as this thesis demonstrates. Chapter five, in particular, moves beyond the concept of disability and turns to queer theory and sexuality studies to consider how conjoinment intersects with questions of gender and sexuality. In the novels discussed in this chapter, conjoinment is used to raise significant challenges with regard to normative understandings of gender and sexual identity formation. In this context, conjoinment operates as a metaphor of compromise or reconciliation; it serves to trouble gender and sexual binaries that govern how the body and sexuality are experienced and understood.

Such metaphoric uses of conjoinment are not limited to questions of sexuality and gender. Indeed, it is possible to argue that the current cultural interest in conjoined twins is partly motivated by the fact that conjoinment poses a challenge to binary thought more generally. As such, the figure of conjoined twins comes to stand for the possible negotiation and reconciliation of difference more generally. It can potentially be used to think critically about a variety of binaries that structure the way in which we perceive ourselves and the world around us, including dichotomies of race, ethnicity, nationality or class, which are continuously debated in scholarship today. Treating conjoinment in this way—as a metaphor to engage with wide-ranging topical ideas—poses ethical problems, as it entails appropriating the specific individual experience of conjoinment for other ends. This appropriation of conjoinment needs to be acknowledged as an integral part of the representations of conjoined twins discussed throughout this thesis as a whole. Despite the potential ethical concerns, it also means that the non-

normative body of conjoined twins, which is so often associated with lack of limitation, is refigured and comes to be seen in terms of potential.

Ultimately, this potential includes raising awareness of the arbitrariness of categories of normalcy. Representations of conjoined twins can radically undermine any distinction between the normal and abnormal and natural or unnatural and highlight that there are many as yet unexplored ways of making sense of ourselves, our identities and our relations to each other. As such, conjoinment serves to highlight that no form of bodily experience or identity, no matter how 'normal' or 'natural' it may appear in the present, is exempt from the category of the 'monstrous'. Quite the contrary, the 'monster' is always evolving and it is crucial to acknowledge this radical openness and to ask what other bodies can be appropriated to 'monstrous' ends to open up to resignification those norms and ideals that shape in equal measure the lives of conjoined twins and singletons. As Rosi Braidotti reminds us, the 'monster' is an open-ended concept, whose meaning and potential can never be contained or predicted:

And because this embodiment of difference moves, flows, changes; because it propels discourses without ever settling into them; because it evades us in the very process of puzzling us, it will never be known what the next monster is going to look like; nor will it be possible to guess where it will come from. And because we *cannot* know, the monster is always going to get us. (Braidotti 1999: 300)

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